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REVIEW

How patient/public involvement impacts the research journey – an overview of the visual impairment research field

[version 1; peer review: 3 approved with reservations, 1 not approved]

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Abstract

Importance – Optimized communication between patients and public, specifically the visually impaired (VI) and VI researchers, is vital for effective patient/public involvement (PPI) in health research.
Objectives - We reviewed evidence outlining effective bidirectional communication strategies in research that improve connectivity between researchers and the public, with specific reference to visual impairment perspectives.
Evidence review - In health research, a disconnect exists between research outcomes and informing patients and public about research advances and novel pre-clinical research, an interaction that is fundamental for mutual benefit. This creates barriers between patients or service-users and the researcher, as researchers are perceived to have higher level technical knowledge but limited know-how of the real-world experience of service users that might impact on the translation of their research.
Findings - Active PPI is endorsed by funding bodies/agencies to facilitate proactive and productive engagement between service users and researchers. Effective communication strategies/tools can help researchers facilitate this engagement.
Conclusions and relevance - PPI inception into mainstream research is protracted but contemporary communication strategies can effectively overcome these issues. We strongly advocate that pre-doctoral students receive PPI training at early career stages, and that patients and public have access to similar training, while Principal Investigators (PIs) are key actors ensuring PPI becomes mainstream in health research.

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Visually Impaired, Public and Patient Involvement, PPI, pre-clinical research, communication, open research



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Plain language summary

Question: How effective are current practices in public and patient involvement for visually impaired service-users in the outcomes of pre-clinical health research?

Findings: This review demonstrates that, though public and patient involvement is advancing in many areas of pre-clinical and clinical health research, in the field of vision impairment research, there is still ample room for improvement in its meaningful impact.

Meaning: More work needs to be done to establish best-practices in communication between pre-clinical ocular researchers and the patients and public that will ultimately benefit from this research.

Introduction

Healthcare is transitioning from focal medical settings to patient and public empowerment[1]. Public includes patients' carers, or family members, prescribing doctors, and end-users. Strong patient and public engagement in health research broadly conforms with ethical/moral and political principles in terms of health policy and methodological outputs[2]. While 'consumer movements' exist in health and social care contexts, their traction in healthcare research has been more recent and nuanced, e.g., health service consumer participation practices are now mandated by governance and policy[3]. In health research, the service-user's voice is often paradoxical to the philosophical and objective position of researchers[4]. Notwithstanding this, and similar to healthcare practices, widening consumer involvement in health research reflects a major paradigm shift in bidirectional communication that empowers the research process. This fosters improved dynamics between funders, researchers, and service users, so that more meaningful research relationships are generated[4].

Service-user engagement in health research is varied in nature, e.g., it can be small or large scale, or single or repeated[5]. Evidence now suggests important roles for consumer involvement in enhancing qualitative health research where thematic research analyses are validated or associated phenomena extended[6]. However, applying consumer or patient/public involvement (PPI) to health research can be tokenistic[7], therefore, more meaningful insights from the service user into research methodologies and outputs are warranted. Already, UK (INVOLVE), and Canadian (CIHR) national strategies have listened to patients' voices and improved patient oriented-research for mutual benefit.

In this review, researchers, patient and public attitudes to visual impairment (VI) research are discussed and national and international strategies facilitating PPI are explored.

Facilitating communication between researchers and service users in a scientific pre-clinical research context

General science communications. Research practices promoting PPI enhance communication between consumers and key stakeholders, for example, across different health fields PPI in patient information development increases understanding of health research[1]. A recent review of best practice principles of PPI in health research identified open and bidirectional dialog between researchers and consumers as driving successful interaction with consumer or patient advocates[7]. Such methods provide an increased understanding of technical language and jargon, and enhance cultural appropriateness, consistent with a recent PPI review[7]. Therefore, including patient advocacy groups during pre-clinical research development *via* effective communication promotes research interest and improves research outcomes[8]. Similarly, peer support initiatives improve communication between active consumers in research[9] and the recent expansion of social media has facilitated communication in health research.

Communicating ocular therapeutic research to VI communities – barriers and impact. Globally, approximately 338 million people are blind or have moderate to severe VI, with numbers expected to increase to 535 million by 2050 due to increasing life-spans and age-related diseases[9]. Engaging with ageing patients brings its own barriers due to lack of comfort with many technological tools for communication and engagement. Blindness and VI interfere with daily activities and impact on physical functions, leading to societal withdrawal, depression, and decreased quality of life (QOL), increasing the barriers to effective communication between researchers and the VI community, issues which can be more problematic with ageing patients[10]. Therefore, effective communication channels for preventative or treatment focused research must take into account these specific challenges. While pre-clinical research is driving improved clinical care practices and promotes the use of new clinical management techniques, the translation of ocular therapeutics and medical device research for VI is more limited and would benefit from the reinforcement of a positive feedback loop between researchers and end-users, therefore research accessibility to communities affected by blindness and VI must be increased.

In recent decades, cultural shifts by researchers, funding agencies and ethics committees have recognized the need for increased patient involvement in research[11]. Research communication barriers, limited PPI participation in vision loss research, and a failure to accommodate some patients in the research pathway, particularly older adults affected by blindness and VI, can adversely impact research outcomes. Importantly, such barriers can be overcome using telephone or alternative communication strategies that the exploit explosion of multimedia channels to improve patient communications and research engagement[12].

Even relatively simple steps can have significant impact for the visually impaired. For example, the American Foundation for the Blind (2018), the National Institute on Aging and also the National Institutes of Health recommend best practice written-materials for individuals with VI; in particular the formatting of shared documents in 18-point Arial font, printed

in black bold on off-white low glare (matt) paper, with graphics limited to one font type and 1.5 line spacing[12]. Previous studies reported that online material/sources were often poorly written, open to misinterpretation, error prone, and unimportant[12]. In response, communication sources are constantly improving to facilitate VI inclusion; for example, simple approaches such as separate audio-descriptions with on-screen videos can benefit patients with VI (UK Gov, 2021). Healthcare providers are key information sources for patients, however, busy clinical settings can interfere with communications, therefore PPI may directly improve knowledge transfer to service users by providing additional, trusted knowledge sources from the VI patient community[13].

Knowledge and engagement with research materials. Patients with chronic long-term conditions such as progressive visual impairment, as well as acute disease leading to VI, recognize the importance and benefit of engaging with health and research communities[14]. In 2019, a patient engagement strategy encouraged PPI in retinoblastoma research that led to positive outcomes[15]. Here, focus groups discussed communication preferences regarding pre-clinical and clinical research trial design and results, and requested high-quality trusted information sources in accessible and understandable formats for families and carers. In 2020, the need for increased bleopharospasm information was identified but it could not be effectively communicated to service users, so a PPI research day initiative was organized[16]. Several formats were used to deliver the information: live wall posters, lectures, and interactive lay-language sessions. Not only were service user research priorities identified but the event was instrumental in generating enhanced communication and education. This demonstrated that unique research engagement activities can facilitate effective communications with patients.

However, for clinicians and researchers, a cautionary note is sounded when reviewing best practice communications in relaying the details of blindness and VI research. Patient hopes for novel therapeutics must be acknowledged while simultaneously countering overly optimistic messaging from media and online sources[16,17]. Balancing expectations through bilateral communication between the research community and service users from early pre-clinical research stages onwards generates pragmatic insights, particularly for pre-clinical research.

Research relevance to patients with VI

PPI in preclinical research on ocular diseases leading to VI. Throughout a project lifespan, PPI requires interactive relationships between academics, clinicians, and service users to conceive, inform, plan, execute, disseminate, and translate research. To be meaningful, these stakeholders must have the tools to be able actively engage in this exchange, with engagement no less relevant and important to VI communities. With clearly identified objectives and contributions, patient and public stakeholders effectively become empowered research partners through project involvement. Designated roles at all research stages ensure that patients influence research pathways, from project conception to clinical delivery, thereby providing focus and enhancing the research impact for target communities[9,11]. Patient researcher interactions/issues are similar across pre-clinical and clinical research programs, including those related to VI[9] and PPI (Table 1).

Despite the benefits of PPI in research programs, this contribution requires individual visual adaption for VI patients. Challenges to meaningful engagement between VI groups and researchers throughout the research pathway must be recognized and addressed by both researchers and also institutional and funding agency infrastructures in order to provide appropriate engagement mechanisms[13]. Importantly, some researchers cannot differentiate between qualitative research with patients (patient experiences provide data with the patient as the subject of the research) and truly interactive research where patients are research partners with views and experiences contributing to decisions throughout the research lifecycle[11,16].

Research relevance to VI patients

Patient roles in ocular drug development (ODD). Research "with" or "by" service users not "about" or "for" patients underpins PPI in research, however tokenistic/symbolic attempts may be used to involve patients and public, without true transparency. Equally, PPI is largely inconsistent and skewed toward early and/or final project stages.

Unequivocally, patients, carers, and their families are experts, however PPI in VI research is often limited to clinical research rather than basic, pre-clinical or translational research. In keeping with recent findings on the contribution of people with VI to research, it is encouraging to see that PPI was documented in initial research processes, in particular research question prioritization and the development of patient-reported outcome measures (Table 1, points 2 and 8)[18].

PPI in the ODD research agenda. VI patient organizations have long been involved in research programs (e.g., Pro-Retina[19]). An example of good practice was seen in 2012, when the James Lind Alliance worked with vision-related patient organizations and eye healthcare professionals in the UK to perform sight loss and vision priority setting exercises. The aim was to identify research priorities, inform funding bodies, and generate additional funding, essentially to ensure that research questions were more pertinent and relevant to those with the conditions. Patients, carers and eye healthcare professionals generated ranked research priorities across 12 eye disease categories. Priorities focused on disease etiology, disease prevention and screening, assessment and management, while ODD research priorities included calls for new and/or better treatments for front to back eye conditions, and non-invasive treatments, including non-surgical alternatives (for cataracts and Fuchs). Critically, it was reported that "It is rare that those with direct experience of conditions are able to influence the research agenda"[20].

Patients and public are more typically involved in patient-oriented priority settings (point 2, Table 1), as seen by research prioritization exercises for inherited retinal degeneration, uveitis, dry eye disease, Sjögren's Syndrome, and

Table 1. How patient/public involvement (PPI) impacts the research journey.

	Interactions/issues	Solutions
1.	- Basic science research questions are far removed from patient needs. - Clinical research questions are scientifically relevant but are they relevant to patient perspectives?	- Research conceptualization via shared leadership ensures unmet medical needs are identified and addressed.
2.	- Not sharing research priorities, questions, and goals relating to unmet clinical needs.	- Early patient/public involvement (PPI) where patient and family perspectives inform research goals and shape aspirations. - Once academic and clinical researchers are open to this, patient/family views can steer research directions, identify overlooked issues, influence study designs, and ensure patient-centered outcomes.
3.	- Patient dropout rates from research projects.	- Improving clinical trial recruitment and retention by directly linking relevant patient populations to research teams.
4.	- Lack of PPI inclusion, poor study insights, disconnect between patients and research groups.	- Improving study design, ethics, methods, tools, and data interpretation. - A meaningful contribution from different stakeholders to all study elements[8].
5.	- Limited PPI on research materials.	- Preparing and overseeing information/documentation in accessible forms for participants (language, communication methods and media, and technology). - Critical for visually impaired communities.
6.	- Addressing common misconceptions between patient groups and researchers.	- Education and information exchange to create expert patient networks contributing to clinical research communities. Dialog can change perceptions where "experiential knowledge is often regarded as less valuable than scientific knowledge"[6,7].
7.	- Future-proofing PPI relationships.	- Evaluating patient experiences so that patient-related feedback informs the design and execution of future research programs.
8.	- Arbitration mechanisms to resolve disagreements between researchers and patients.	- Outcome prioritization conversations between stakeholders to resolve ocular condition issues[9,20].
9.	- Ensuring a happy medium.	- Disseminating and applying impactful results, and ultimately, improving patient care. - PPI ensures open and transparent scientific research by research teams to generate increased confidence in research data in target audiences, which in turn drives and improves research outcomes.

retinoblastoma[15,21–23], Such research priorities set with PPI include the need for safer and efficacious treatments with reduced treatment burdens (e.g., reducing hospital visits and increasing treatment adherence). Evidence shows that research prioritization can be incorporated into ODD research at basic, pre-clinical, and translational stages to promote new blindness-related research and identify new treatments or alternative drug delivery methods to alleviate patient burdens.

PPI-based research priority and agenda development has become mainstream and will continue, even where patients do not lead the agenda. Both Cochrane Eye and Vision systematic reviews[5] and the Lancet Global Health Commission on Global Eye Health[24] established priority-setting exercises and inputs from different stakeholders. This includes patients, carers, and the public, who need to work in collaboration with researchers to systematically assess the nature and extent of different research questions and identify key research and action areas in delivering research for universal eye health by developing research "in partnership" with patients.

PPI in clinical research outcomes. Patients have evidentially influenced VI research by determining clinical research outcomes in several ocular conditions (point 8, Table 1)[9,25]. Patient experiences and associated benefits are more actively considered by clinical researchers when focused on developing appropriate outcome measures for OD research. Studies have reported a disconnect between measured clinical research outcomes and important patient outcomes[26]. This is critical in ODD as patients are the ultimate consumers/beneficiaries from successful translational research. In developing treatments for low vision levels, designing functional vision assessments for everyday life is vital. Patient reported outcome measures (PROMs), evaluating health-related QOL measures, are now

widely used to assess new clinical trial treatments; of importance in pediatric ophthalmology, and PPI facilitated age-appropriate PROM questionnaires[27].

Additional PPI, in medicine research and development, was recommended by the European Patients Academy on Therapeutic Innovation (EUPATI), where patient organizations worked with academics, non-profit organizations, and pharmaceutical companies[28]. In this instance, patient experts and advocates engaged effectively with relevant authorities to influence medicine development. Again, most PPI was at initial (e.g., fundraising, informed consent, and ethics) or project-end stages (e.g., Health Technology Assessment, post-study communications, and dissemination). However, it is recommended that patients should be part of the entire research and development roadmap, participating on advisory boards, ethics committees, and trial programs[29].

Helping scientists to make research accessible

To maximize the research impact, scientists must make research accessible and share it with service-users. Funding agencies must promote national policies and programs to prioritize health literacy using clear information, effective communications *via* relevant routes and using relevant tools, and education.

Typically, scientists are not professional communicators with public or patient cohorts, and are inexperienced in requesting their involvement as key stakeholders[30]. Time commitments and a lack of guidance/training on how to effectively communicate with service users with differing functional abilities, are major challenges for scientists implementing PPI in preclinical research[31]. Clear, effective communication which considers the service user's unique requirements (e.g. visual impairments or hearing impairments) is required for PPI to be successful. This must occur throughout the lifecycle of a research project and will help maximize research impact, while ensuring research findings stay accessible.

Beyond involvement on advisory panels, meaningful patient engagement in multidisciplinary research advisory boards requires mutual respect to add value to research. Patients have developed research registries, completed priority-setting exercises, developed websites to communicate information, and have demonstrated their ability to help write grants, and these achievements must be recognized and better utilised[8,32]. However, the collective patient voice is moderated by context, fragmentation, limited resources, and the competing needs of different patient groups[9].

Science communication models. Dissemination, public participation, and health literacy socio-ecology models have been formulated to assist with science communications (Figure 1) and these should be reviewed and adapted to accommodate the challenges experienced by people with VI.

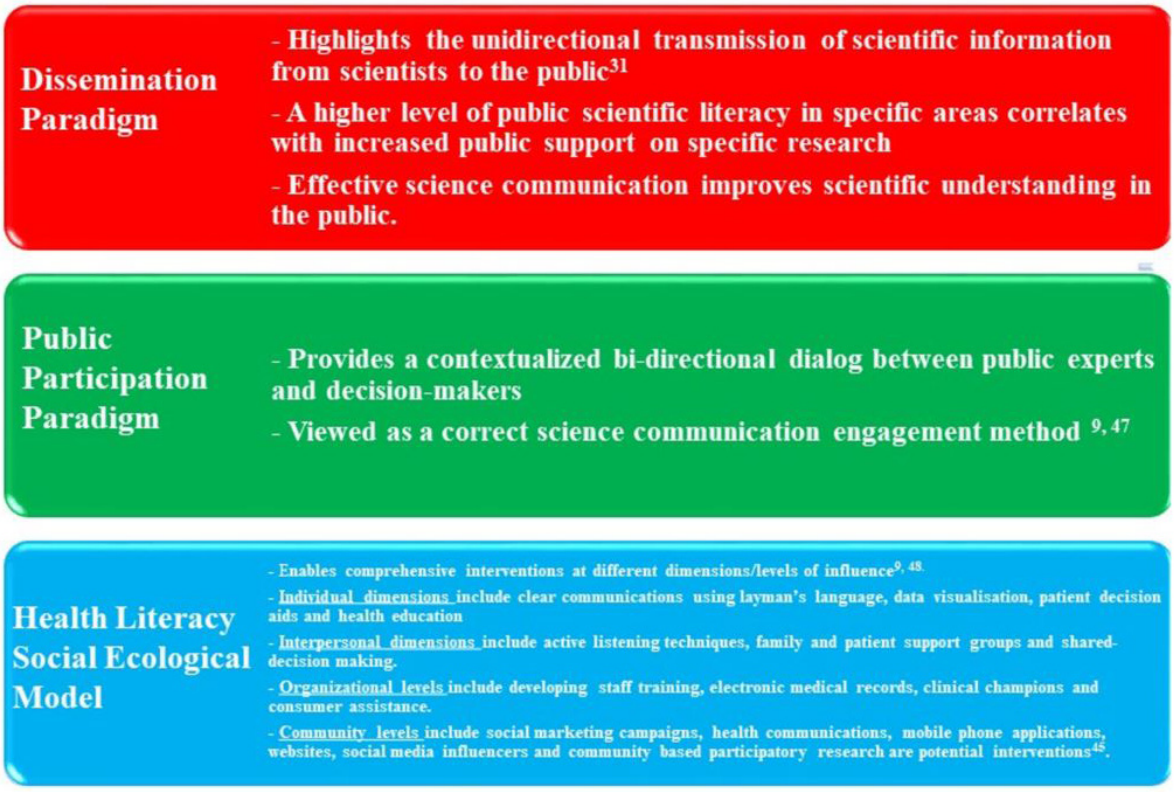

Figure 1. Dissemination, public participation, and health literacy socio-ecology models which facilitate science communications.

Researcher communications tools. Researchers should identify relevant and measurable health literacy outcomes, so that they are competent, informed, and inclusive of shared health decision-making factors. While a dearth of evidence exists relating research outcomes to effective communication of scientific results and engaging PPI in research[33,34], researchers can and should use different tools to effectively engage with groups of all capabilities (Table 2).

Table 2. Tools and methods facilitating improved researcher/service user communications.

Communication tools and methods	Role/function	Impact	References
Publicly accessible scientific journals; 1. Public Understanding of Science 2. Journal of Science Communication 3. Public Communication of Science and Technology Network	- Communicating research findings to the general public. - Engaging public audiences in science.	- Communication with peers in the same subject area.	20
Infographics; Communicating ***via***; 1. images, 2. icons, 3. text, 4. charts, and 5. diagrams	- Combine texts/images to represent complex information in an attractive and meaningful visual format.	- Research papers, promoted using infographics on social media, are associated with increased 'altmetric' scores. - Patients gain a better understanding of their condition and making informed decisions.	35–37
Research Impact Tool - Development of a tool rating the impact of research publications on society.	- Defines the aim of the investigation. - Defines the extent to which authors translate their scientific findings into societal actions. - Identifies the level, status, and groups targeted by this translation.	- The societal impact factor of a publication should consider the effect of the publication in a wide range of non-scientific areas. - The motivation behind the publication, and efforts by the authors to translate their findings must be considered. - The tool provides valuable insights for further research and practical applications in the topic area.	8,12,35
Opensource - User-friendly iterative tool to incorporate patient/public involvement (PPI) into research.	- The "PPI Ready" researcher canvas is a visual design tool based on a business model examining barriers and concerns incorporating PPI.	- Provides a strategy for increasing the value and impact of research.	38
Health Literacy Instructional Model 1. Tele-Medicine 2. Artificial intelligence in ophthalmology	- Global perspective describing specific competencies.	- Emphasizes equity and an accessible media environment for all.	34,37
Preprint Servers - Preliminary versions of scientific manuscripts shared by researchers to online platforms before peer-review and publication in academic journals.	- Maintains open lines of communication with the public. - Preprint servers are publicly available online archives that host preprints and associated data.	- Facilitate the immediate sharing of research data such that searchers do not have to wait so long to find out about research that's already been done.	38
Social media platforms	- 'Video blogging' or 'vlogging' on social networks provide a wider outreach to service users.	- Visuals and social media help create global networks for science communication which are followed by researchers, policymakers, and the public. - The management of high noise to signal ratios, dissenting thoughts, messaging and time limits must be considered.	21,34,38
Smartphone applications - Easily downloaded applications improving health awareness.	- Rapid access to online research and health information.	- Further research is required to validate smartphones and applications for improving visual assessments in low-resource settings, inpatient wards, or traveling clinics.	39

Scientists must bring in service users during the development phase of their research, beyond academia, to credibly develop and communicate socially relevant science[40,41] with expertise, knowledge, accuracy, and trust[42]. Memorable and meaningful messages should be delivered through accessible routes, and an audience-tailored, jargon-free message must be framed within a larger context, while analogies and metaphors, indicative of an elevator pitch, can highlight issues and exert immediate and powerful effects. This will address gaps in understanding, as not all service users understand specific research and medical jargon.

The impact of PPI

Impact on research communities. Ensuring more patient-centric research activities and improving access for patient engagement within the research process are core PPI principles. While consequential impacts on patient outcomes are important success markers, the impact on research communities is critical as it reinforces the community's position in research. Given the limited information on the impact of PPI in preclinical ocular therapeutics research, several reviews on more general PPI applications were analyzed to help identify critical issues for and barriers to better engagement with people with VI.

In a scoping review, Modigh *et al.* reported on impacts relating to research processes in 24 reviews, with 11 reporting on the impact to researchers[35]. Research processes tended to focus on research agendas and questions. In terms of researcher impact, a significant focus fell on the importance of "knowledge and understanding the community". The authors highlighted a review where increased public enthusiasm for research projects was linked to increased motivation for participation[43]. However, the authors also highlighted a report reviewing the impact of older individuals' in PPI, and discussed the negative impact caused by cohort organization and coordination challenges[44]. The authors indicated that several articles discussed the increased research credibility in the wider community when researchers engaged in PPI, while four publications suggested PPI challenged researcher beliefs and attitudes[44].

In primary care research, the perceived impact of PPI by principal investigators (PIs) is largely positive[44]. PPI activity is broadly seen to provide several benefits for researchers: improved information clarity, increased recruitment and follow-up rates with validated findings, and relevant outputs for both clinicians and patients. However, by contrast, one study[36] indicated that PIs perceived a minimal impact from PPI in developing grant applications and managing and conducting research. An analysis of 200 scientific and health research grant applications showed that only 24% included early-stage PPI inputs, while 57% highlighted PPI initiatives during the execution of research projects. Also, 67% of PIs perceived little impact on their own institutions, with in-house concerns related to the assumed negative impact of funding diversion, the need for improved information technology and other resource costs associated with these activities. Other potentially negative impacts of PPI included the opportunity costs of the activity, while some PIs reported "minimal perceived impact" of PPI in managing and conducting their research.

One report suggested that simply 'measuring' an impact risked distorting how PPI was conceptualized and practiced, and possibly ignored observed negative impacts[44]. Such perceived negative impacts on researchers included the need for additional resources, time and skill requirements, and stress and tension. Importantly, an early report on the impact of PPI stated that the "search for more 'robust' evidence of impact remains a holy grail"[44].

While numerous studies report the impact of PPI on researchers and research communities, one review showed that PPI is skewed toward research by established researchers and in particular PIs[36]. While individual PI focus is important to the patient community, the authors of this review suggest that considerable PPI awareness and training should be instigated by all PIs during doctoral training. It seems clear that when the involvement of service users is considered during the initial project stages, this benefits researchers, research communities, and research careers.

Patients (not necessarily VI service users). While PPI undoubtedly facilitates the development of more useful treatment options, the evaluation of service-user participation is sparse, in particular for VI patients, and therefore more research is required. Once it becomes clear how PPI beneficially affects patient cohorts, more evidence of positive impacts will emerge and filter to every participant throughout the research process[45]. In areas where PPI is prevalent, e.g., cancer and terminal illness research, key themes drive patient and carer volunteering and participation[33,46]. Exemplified by patient goals, these themes improve disease/condition knowledge and treatment research, and ultimately "contribute to the greater good" of society[37,38,47].

For patients, an understanding of pre-clinical research should "increase self-assurance, reduce anxiety, generate improved insights on one's ailments, provide more knowledge on the effects of medicines, increase self-acceptance, and improve social contacts between the chronically ill"[48]. Therefore, with more PPI in healthcare research, the likelihood is that outcomes for these end-user groups will improve. While research is limited on the motivation behind PPI, two PPI categories are posited: social and personal: "Social motivation refers to notions of altruism, influencing research, and changing services for the benefit of others, while personal motivation includes opportunities for individuals to develop confidence, learn new skills, and derive positive outcomes from their ill-health experiences"[34,39,49].

Unquestionably, more research is required to quantify PPI benefits in pre-clinical research, and in particular how these benefits can be optimized for the VI community. As funding bodies push for more PPI inclusion at early research stages, patients, carers/families, and researchers must be made better

aware of the challenges and the benefits so that ethically sound PPI standards are maintained and communication strategies are tailored, particularly for vulnerable members of society.

Conclusions

Contemporary research has largely undocumented the experiential benefits patients derive from participating in pre-clinical research. While tacitly accepted, effective PPI ultimately improves research outcomes for researchers and patients, but the patients themselves do not fully understand the impact. Therefore more research is required to understand individual roles in research development and execution and in mechanisms that would enhance patient and the public (cohort) participation. In particular, overcoming the unique and specific barriers to the VI patient for effective PPI in ocular research is critical. It is undisputed that effective communication in health research promotes good science. Researchers can exploit several established management strategies to engage more effectively with service users; specifically, pre-doctoral PPI training during formative years and a PI-driven focus on incorporating PPI into grant writing. Ultimately, this will ensure more positive engagement with funding bodies and service users.

Data availability

No data are associated with this article.

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Version 1

Reviewer Report 20 June 2024

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Emmy Racine
University College Cork, Cork, County Cork, Ireland

Dear Authors,
Thank you for the opportunity to review your research paper. I have included some suggestions below on how it could be improved.

1.Abstract: Unclear how the objective you have put forward in the abstract fits with the title of your paper. Your title suggests you are exploring the impact of PPI on VI research, however your objective is more about reviewing bidirectional communication strategies that improve connectivity between researchers and public in VI research. I suggest reviewing title and objective to ensure they accurately reflect the content of the paper.

2.Plain language summary- This plain language summary does not describe the same paper as is described in the abstract. Your “question” is significantly different to the objective described in the abstract. Your findings and meaning are also different to what is described in the paper. And some terms are not sufficiently defined (e.g. pre-clinical, public and patient involvement, ocular).

3.Introduction- The overall aims and objectives of this research are unclear. Significant variation in how they are presented throughout the paper. Furthermore, your findings and conclusions as presented in the abstract, lay summary and main body of paper seem to address a different aim to what is described.

4. I suggest reframing Introduction to:
-Overview of VI/ VI research (see point 5 below)
-Description of the gap/problem in VI research that you are trying to address
-Introduction to PPI as a potential way to address that gap
-Therefore, the aim of this research is to...

5. Main body of paper- The ‘Communicating ocular therapeutic research to VI communication-barriers and impact’ paragraph is very well- written and very relevant as the opening paragraph of the introduction. This information is really important to readers who are not familiar with VI

research and should be first and foremost in the paper.

6.In the 'Research relevance to VI patients' paragraph, you have included a definition of PPI, this is needed much sooner in the Introduction section of the paper (see point 4 above). Also, don't forget to include reference for this definition.

7.There is a lack of detail throughout on the methodology employed for this literature review. Suggest including a paragraph on your methods, search terms used, keywords, search timelines, types of papers included, brief overview of research topics/ areas.

8.Table 1 – Is the information in this table relating to PPI in general or PPI in VI research? You need to be explicit about this throughout the paper as it seems to be conflated throughout.

9.Figure 1- This text in this figure is difficult to read, particularly in the 'Health Literacy Social Ecological Model' section. As this is a figure and not a table, I suggest presenting this text in a more graphic/ illustrative way.

10.Table 2- This is a useful table however it could be presented in a more visually appealing way. There is a lot of text here and it can be difficult to read at times due to the different sentence structures used (i.e. Sentences starting with/ without verbs).

11.Your section on the impact of PPI is not specific to VI research as you did not find any relevant papers to include. However, the fact that there are no relevant papers is an important finding and should be highlighted as such.

12.It is difficult to see how your conclusions directly address the research question/ objectives presented at the beginning of the paper. Some tweaking needed here to make it more explicit.

Overall, this paper has the potential to contribute to the field of PPI in VI research. However, the structure and format of the information presented needs to be revised to make this contribution clear. Thank you.

Is the topic of the review discussed comprehensively in the context of the current literature?

Partly

Are all factual statements correct and adequately supported by citations?

Yes

Is the review written in accessible language?

Partly

Are the conclusions drawn appropriate in the context of the current research literature?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Public and Patient Involvement (PPI) in Health and Social Care Research.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Reviewer Report 08 June 2024

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Cathryn Smith
Cardiff University, Cardiff, Wales, UK

Dear Authors,

Thank you for the opportunity to review your paper. You clearly provide an overview of patient-public involvement in visual impairment research. Please take a look at the recommendations below to enhance your potential paper:

- There is no information on how you searched, reviewed and analysed evidence, more information on this would be beneficial for the readers and enhance the transparency of the review study.
- You use different terminology for patient/public involvement, this includes PPI/service user and consumer, it would be beneficial to use one and stick to this throughout.
- The definition of PPI under the heading “patient roles in ocular drug development (ODD)” needs to be referenced and I suggest you move this to the start of the study to inform the reader of what you mean by PPI.
- You have written about how PPI are involved in clinical research rather than other types, why is this? I felt as a reader I would like to know why this is the case – is there a reason?
- Under the heading “helping scientist to make research accessible” you have not really answered or discussed this – how could scientist and researchers use these recommendations to establish PPI relationships particularly for VI?
- I could not read figure 1 – the colours and font need changing.
- Having a clear insight into the methodology as recommended above would allow the reader to be more aware of the studies you reviewed and why.
- The section on impact could relate more to VI and how it can have a positive affect on research in this field, I feel this is lacking in this section and you have taken a broader approach to this.
- You mentioned national and international strategies in PPI, reference to NIHR and the UK standards for public involvement would add to the study. https://www.nihr.ac.uk/documents/patient-and-public-involvement-and-engagement-resource-pack/31218 and https://sites.google.com/nihr.ac.uk/pi-standards/home

Is the topic of the review discussed comprehensively in the context of the current literature?
Yes

Are all factual statements correct and adequately supported by citations?
Partly

Is the review written in accessible language?
Yes

Are the conclusions drawn appropriate in the context of the current research literature?
Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: public health nursing, dementia, PPI, end of life.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Reviewer Report 11 May 2024

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Jennifer Preston
University of Liverpool, Liverpool, England, UK

Terminology in the article needs addressing, it goes from public, patient, consumer, service-user involvement, consumers etc, this doesn't read very well. The authors also use participation, engagement, and involvement interchangeably, if the article is about involvement just describe involvement practices.

The actual title doesn't reflect the content of the article. A large section of the article describes how patients can contribute to VI research at various phases of the research process. It would have been interesting to have patient views incorporated into this article about their experiences of involvement. The section on impact describes what we already know about the impact of PPI in health research, it doesn't add anything new.

It is quite repetitive in parts with various references to what PPI is, although important it doesn't need to be repeated throughout.

Is the topic of the review discussed comprehensively in the context of the current literature?
No

Are all factual statements correct and adequately supported by citations?
No

Is the review written in accessible language?
No

Are the conclusions drawn appropriate in the context of the current research literature?
No

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: I have worked in the field of patient and public involvement in health research for 19 years.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to state that I do not consider it to be of an acceptable scientific standard, for reasons outlined above.

Reviewer Report 06 March 2024

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Marina Charalambous
Department of Rehabilitation Sciences, Cyprus University of Technology, Limassol, Cyprus

Dear Authors,
Thank you for the opportunity to review your paper on "How patient/public involvement impacts the research journey – an overview of the visual impairment research field". Your review explores the researchers', patient, and public (PPI) attitudes to visual impairment (VI) research and discusses the strategies facilitating PPI in this field. The paper demonstrates clear writing and effectively informs the reader on the subject matter. Below, you will find minor recommendations for potential paper enhancements:
1. The authors adeptly contextualize the research communication barriers, inadequate knowledge transfer to service users, and limited participation of patient and public involvement PPI in the VI research field within the introduction. However, there is a notable absence of information regarding the methodology employed to conduct this review study. It would be beneficial to inform the reader about the guide utilized to extract the studies included in this review paper, such as the PRISMA protocol. Additionally, providing details about the search sources, keywords,

time frame of the search, and inclusion or exclusion criteria would enhance the transparency and rigor of the study.
2. In the "Paragraph Researcher communication tools" on pages 7-8, it is important to acknowledge patients with visual impairment (VI) secondary to acquired neurological diseases (such as ALS, MS, Stroke, etc.) or other conditions, who also present with complex disabilities including reduced mobility (paresis or paralysis of the lower and upper limbs), diplopia, and communication deficits (aphasia/dysarthria). These individuals face significant challenges in accessing clinical information and meaningful involvement in research teams due to their multifaceted disabilities. These difficulties underscore the importance of developing inclusive communication strategies and accommodating environments to facilitate their participation in research endeavors (Browne & Dorris, 2022).
3. After paragraph 2 under the Subtitle "Helping scientists to make research accessible" (p.6), it is crucial to incorporate recommendations concerning how scientists and researchers can establish the foundations of patient and public involvement (PPI) before engaging patient partners with communication challenges (and VI) within the research team. These recommendations are pivotal for promoting the meaningful involvement of patient partners with VI in research teams.
4. Moreover, it is important to incorporate in the results of the paper various PPI frameworks, from the VI sector or other conditions that serve as a valuable guide for researchers seeking to include individuals with acquired disabilities in research teams. Such frameworks emphasize the importance of adjusting and co-developing written material and resources with patient partners, facilitating their engagement within the research team through adaptable induction procedures, codesign methodology, etc. Integrating these recommendations and frameworks will enhance the accessibility and inclusivity of patient partners in the field of VI as well.
5. Please revisit Figure 2 to adjust the font sizes to enhance readability, particularly in the "blue" section.
6. In paragraph 1 on page 7 under the subtitle "Patients (not necessarily VI users)," it is essential to incorporate qualitative studies that focus on the views of patient partners on PPI in other clinical populations. These studies will shed valuable light on the experiences and perspectives of individuals with disabilities in engaging in PPI initiatives, thereby enriching the understanding of broader inclusion practices within research activities. Citation: Browne, J., and Dorris, E. R. (2022). What Can We Learn From a Human-Rights Based Approach to Disability for Public and Patient Involvement in Research? Front.Rehabilit.Sci.3:878231. doi:10.3389/fresc.2022.878231

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Is the topic of the review discussed comprehensively in the context of the current literature?

Yes

Are all factual statements correct and adequately supported by citations?

Yes

Is the review written in accessible language?

Yes

Are the conclusions drawn appropriate in the context of the current research literature?
Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Patient and Public Involvement in People with Aquired Communication Impairements

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.