

Public and Patient Involvement in Vision Research - A Multi-Stakeholder Workshop

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Background:

Public and patient involvement (PPI) serves to create a working relationship between those living with and affected by sight loss and those undertaking research to enhance understanding and to develop therapies. It is research carried out 'with' patients so that their perspective play a key role in informing and shaping the R&D pathway. This approach can lead to improved quality in the research process and higher impact for the results of such research.

Goals:

- To empower the sight loss community and help them to recognise their role as important stakeholders in guiding research and healthcare
- To identify starting points for vision researchers and clinicians wishing to incorporate PPI in to their work
- To identify common ground between researchers and the sight loss community as they work together to identify the WHAT, HOW, WHY of PPI

Process:



CANVAS

- Survey sight-loss clinicians and researchers to identify appetite for, and barriers to, PPI
- Survey sight-loss community to gather perspectives on PPI



BUILD

- Design workshop, informed by patient-informed steering group
- Recruit external facilitators



LAUNCH

- Hold a multi-stakeholder event: clinicians, researchers, people with sight-loss, family members
- Run interactive sessions where participants learn about the WHAT, HOW and WHY of PPI

Workshop Activity Sample:



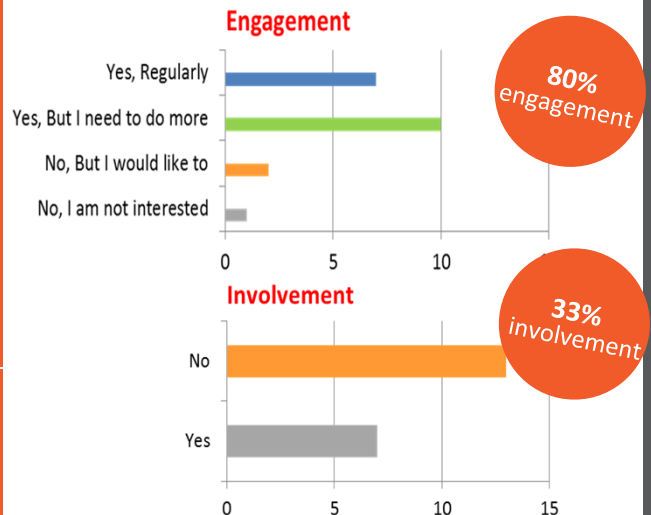
SORTING THE RESEARCH CYCLE

Participants were invited to sort how they thought the research cycle runs

Workshop Outcomes:

Pre-Workshop Researcher Survey

80% of respondents were from a basic or translational science background



- When asked why they neglected involvement, researchers stated a lack of confidence in having sufficient knowledge surrounding PPI.
- These results highlighted the need for this Workshop.

Post-Workshop Survey



100% better informed

Understanding the research cycle and where PPI fits proved most beneficial for all attendees



- Increased understanding was achieved as evident by additional uptake of PPI initiatives post-workshop.
- Next workshop will address barriers to PPI and identify solutions.

"I felt that it was a really well run event and I wouldn't change it. I gained a better understanding of the difference between engagement, involvement and participation and how people can be involved at all stages of research."

PPI Contributor

"I felt really motivated following the session. I am confident that our group can now incorporate more PPI into our research."

Vision Researcher