



NICE Knowledge Exchange Seminars

Knowledge exchange seminar series – session 4: Patient expert training

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ABSTRACT

Introduction: A second knowledge exchange seminar series was organised as a part of the collaborative project between NICE International and Indian health outcomes, public health and economics research centre (IHOPE) to develop and implement evidence-based clinical guidelines in India. The training of patient experts as a part of the committee is an important step in any committee's development.

Aim: To describe how IHOPE plans to provide training to patient representatives on its guideline committees.

Conclusion: Continuous feedback from patient experts improves their experience of working in guideline committees and helps keep the training provided to all patient experts relevant and current.

Keywords: Guideline committee, Guidelines, Patient training, Training

This paper is the fourth in the second series of this collaboration, and further, information on the other papers in the first series can be found at: <https://ihopejournalofophthalmology.com/issue/2022-1-2/>.

INTRODUCTION

The guideline process can be time-consuming and intense, there may be complex and technical evidence to discuss, and the tight timelines can be very challenging. Patient experts are often inexperienced with guidance development methods, committee meetings, and being equal with clinical experts. It is important to provide training and support to new patient experts when they join a guideline committee to ensure that they are able to participate meaningfully. This training should focus on establishing the responsibilities and expectations of the patient experts and provide them with the confidence to participate in the process effectively. The objective of this article is to describe how IHOPE plans to provide training to patient representatives on its guideline committees.

PATIENT EXPERT TRAINING

It is important to provide clarity on the responsibilities of the patient experts, which is to share their experiences and insights with the committee and help the committee interpret the evidence presented. There is often limited research evidence on patient views, preferences, and experiences

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which highlights the importance of sharing patient views with the committee. This involves challenging other committee members on key issues such as which outcomes are most important to patients, and what would constitute a meaningful difference between different treatment options. This helps the committee identify specific challenges being faced by patients.

Given the responsibilities placed on patient experts, it is vital that the secretariat supports them and provides training to equip them in their role. This should start during the recruitment process when a job description and information on the role and responsibilities should be provided. Other information that should be provided includes an overview of what is expected of patient experts, the approximate time they would need to devote to the guideline (in terms of preparatory work, attending the meetings, and reviewing draft documents), how to claim expenses for attending meetings if appropriate as well as who to contact with any queries.

For some guideline developers, for example, at NICE, a dedicated support person is allocated to each new patient expert. This named contact provides support to the patient expert throughout the whole guideline development process. They have scheduled contact points throughout the process to provide information on the next stages and what their role will be, and monitor their experience on the committee. It may also be useful to have a buddy system whereby new patient's experts are paired with an experienced patient expert to ensure they get a real insight into the process and what is required. This support is integral for the patient experts to contribute meaningfully to the guideline development process.

Patient expert training should provide, the patient experts with the knowledge required to understand the guideline development process and how committees work. This should include an overview of systematic reviewing, what is required of them during the meeting, and strategies for engaging positively with other committee members and dealing with disagreements. As guidelines are developed by committees, it is often necessary to compromise to reach a consensus, and the resulting decisions may not always be acceptable to the patient experts on the committee.

CONCLUSION

Continuous feedback from patient experts improves their experience of working in guideline committees and helps keep the training provided to all patient experts relevant and current. Regularly scheduled contact points with support available throughout the process give patient experts the opportunity to report how they are getting on, whether they need additional support or training, and if their voice is being heard during the committee. There should also be a mechanism for confidential exit surveys which can be then shared with the secretariat, this feedback can then be used to provide training to Secretariat staff, committee chairs, and other committee members on how to work with patient experts and to recognize the added value that patient experts bring to the process.

Declaration of patient consent

Patient's consent not required as patients identity is not disclosed or compromised.

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Conflicts of interest

There are no conflicts of interest.

Use of artificial intelligence (AI)-assisted technology for manuscript preparation

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