

PATIENT ENGAGEMENT IN CLINICAL GUIDELINE DEVELOPMENT IN ERN CRANIO AND GENTURIS

2022

Activity	Patient Engagement in Clinical Practice Guidelines
Area	Clinical Practice
Duration	1,5 hours
Contact	Gareth Davies

1. SUMMARY

i The ePAG Good Practice Call on 'Patient Experiences with CPG development' on the 31st of January 2022 gives an overview of how patients can be involved in the different stages of the Clinical Practice Guideline development process and the examples from ERN CRANIO and GENTURIS show very different guideline development approaches with the former being more of a learning curve with formal ePAG representation only being brought in at the final stages of the development experience, though patient surveys had been undertaken by clinical leads near the start of the process.

2. INITIAL SITUATION

i The ERN Guideline Methodological Handbooks which the Spanish Consortium developed for the ERNs in the context of the ERN Clinical Practice Guideline Programme provides a methodology for ERNs to develop guidelines. The handbooks include recommendations on patient engagement in the guideline development process. ERNs adopt different processes and methodologies to develop Clinical Practice Guidelines.

Max 200 words

3. CONTRIBUTION TO PATIENT ENGAGEMENT AND/OR IMPROVEMENT OF CARE

i *Patient input is critical to ensure the final guidelines will answer the questions that are important to them. Further, patient input is vital to identify evidence gaps in areas they consider important e.g. Discomfort.*

Engaging patients in the guideline development process within ERN CRANIO and GENTURIS shows the added value of patient engagement and also where patients' can contribute to the development process.

With a clear methodology on guideline development in ERN GENTURIS significant improvements were made that ensure patient involvement throughout all phases of the development process. Patient representatives were able to contribute to the literature research, nominating experts for the extended writing group and the Delphi survey, participate in the discussions on the recommendations, developing a lay version of the guideline summary and their contributions are recognized in the publication through co-authorship and acknowledgments.

4. SUCCESS FACTORS

i *Good communication between the ePAG advocates and ERN coordinators is imperative in ensuring effective guideline development. In the case of GENTURIS, it was helpful that a rough timeline with information regarding when to expect patient input throughout the process and from the beginning was helpful to ensure good engagement and to help ePAG advocates to stay motivation throughout the development process and even during quieter times i.e. literature review. ePAG advocates were involved right from the early discussions on the scope of the guidelines, through the actual development process and also in the dissemination patient representatives played an important role, to make sure that the guidelines are being used across Europe. It is also useful to consider an open call to recruit representatives with relevant experience and to try to have representatives from different countries / health systems and with different backgrounds. ERN patient groups can support with this.*

5. LESSONS LEARNED

i *Patient input throughout the guideline development process is critical to ensure that the guideline will answer to the questions which are important to patients. Patients are the best people to comment on how you weigh up benefits and harms and your values and preferences e.g. Accessibility of testing in local health settings, discomfort, anxiety of procedure, cost as these areas often have no research evidence from the main literature review. With a clear methodology on guideline development in ERN GENTURIS significant improvements were made that ensure patient involvement throughout all phases of the development process. The experience of patient engagement in the guideline development process in ERN CRANIO was ultimately a positive learning curve which will guide future guideline development processes.*

6.

Selection criteria:

1. All sections are complete
2. The description of the good practice is clear
3. The good practice is innovative in terms of its impact and results
4. The good practice is easy to replicate