

Involving a haemodialysis patient in a systematic review: A clinician and patient perspective

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Introduction: In recent years, there has been a drive to include patients in the design and implementation of research, through the incorporation of Patient and Public Involvement (PPI) representatives. This is to ensure research is relevant, meaningful and develops feasible interventions. INVOLVE have provided guidance on PPI in research. However, there is little guidance on how to include patients in a systematic review.

We completed a systematic review (CRD42018094656) examining studies that compare cannulation techniques for haemodialysis. We decided to include a patient undergoing regular cannulation for haemodialysis, to assist in evaluation of studies.

Methods: The patient included had an interest in supporting the systematic review and is an amateur writer with good English language skills. Support activities were designed with him, to facilitate his involvement, ensuring he was fully able to appropriately interpret and appraise studies. This included:

- 1) A clinical librarian provided bespoke teaching on how to critically appraise research
- 2) A glossary of terms for the patient to refer to whilst reading studies
- 3) A summary of data extraction from other authors was provided with each article
- 4) A bespoke review form designed to capture his own perspective on each study, which included an opportunity for him to highlight any areas of uncertainty.
- 5) Following completion of the bespoke review form, the patient had opportunity to discuss findings with the lead researcher.

All activities coincided with the patient's normal haemodialysis treatment.

Following data extraction from other authors and development of themes for discussion in the narrative synthesis, the information from the patient review form was incorporated into the narrative synthesis. Following completion of the systematic review, a summary of his experiences of being part of the systematic review was developed with the patient.

Results: The results from the patient review form and discussion with the patient indicated he understood the studies he reviewed. The patient's perspective highlighted aspects related to studies that were relevant and incorporated into the narrative synthesis. This included providing context to pain results and a reminder of the consequence of changing practice based on research where bias potentially influenced results. All the points the patient highlighted were also identified by other co-authors, however the patient's perspective brought a new, different and appropriate emphasis, reminding the team of the practical application and potential consequence of findings for haemodialysis patients.

The patient felt all the tools to facilitate his involvement were useful and assisted his reviews of studies.

Discussion: Including patients in systematic reviews provides a different perspective on the relevance and interpretation of research findings. However, their involvement requires facilitation and resources to ensure their contribution is valuable and the rigor of systematic review is maintained. For this patient, the tools developed facilitated his involvement and enabled him to provide an independent opinion on studies.

Further work needs to be completed on how to include patients in systematic reviews and formally evaluate

their contribution. However, in this systematic review, this patient's contribution added value, meaning and context to the findings.