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## P114 -The use of Patient-Reported Outcomes in patients with End Stage Renal Disease requiring treatment with Haemodialysis: a narrative review.

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There is increasing interest in the integration of patient-reported outcomes (PROs) into health care research and clinical practice for the benefit of patients with end stage renal disease receiving haemodialysis (HD). In routine care, PRO data may be used to support service delivery through benchmarking and audit, or to inform and enhance the care of the individual patient by improving patient-clinician communication. In a research setting, PROs can be utilised as a patient-centred primary or key secondary outcome in clinical studies and provide valuable information on the efficacy, tolerability and effectiveness of interventions. Despite clear evidence and recommendations supporting greater uptake of PROs, including prioritisation by patients, their use in kidney disease remains limited. This narrative review aims to map the emerging evidence surrounding the implementation and use of PROs in HD research and routine care.

### Methods:

To review the current use of PRO endpoints in HD trials, a search of all HD studies recorded on the ISRCTN registry was conducted. Trials listing a PRO as a primary or secondary outcome were included. To identify papers discussing the implementation of PROs in HD settings, research and routine care, a search of Medline, Embase and the Cochrane library was undertaken; supplemented with a citation search and contact with experts. Data from all included papers/studies was extracted, synthesised and summarised to identify implications for practice.

### Results:

220 HD trials were registered on ISRCTN between 2002 and 2018. Of which 38 (17%) included a PRO: 9 (4%) as a primary outcome and 29 (13%) as a secondary outcome. The review highlighted issues for further enquiry including inconsistency in PRO measure selection and lack of detail regarding administration. The search demonstrated a wide variation in chosen measures to assess outcome domains, which may reflect the current difficulty in identifying HD-validated PROs capable of capturing core outcomes which have been ascertained as important to all stakeholders, particularly patients.

Regarding the implementation of PROs in routine care, the search strategy identified 513 titles/abstracts: after 265 duplicates were removed, 248 titles and abstracts were screened. Using predefined search criteria 34 were selected for full text review; 23 papers were further excluded. Using citation searching and expert advice a further 8 articles were included, bringing the total number of papers involved in the synthesis to 19. The synthesis identified themes which included the challenges of PRO measure selection, the potential of multiple use of PROs and IT complexities associated with implementation of electronic PROMs.

### Conclusion:

Despite evidence and recommendations for PROs use, including prioritisation by patients and other stakeholders, use in nephrology settings is inconsistent. The potential multiple use of PROs requires careful coordination to avoid burdensome collection and feedback schedules.

This review outlines the current use of PROs for patients with end-stage renal disease receiving HD treatment and identifies a roadmap for increasing the evidence base and identifying the significant

methodological and operational challenges within HD settings which need to be addressed to ensure these important patient-centred outcomes are routinely captured for the benefit of future patients.