

Digital vs Paper Data Collection: Benefits for In-Hospital Haemodialysis Patients

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Introduction

Patients on haemodialysis (HD) treatment face complex care pathways, high treatment burden, lower than average quality-of-life (QoL) and have reported frustration or dissatisfaction with their personal experiences of care. A reliable method of assessing and collecting patient-related outcome measures (PROMs) has proven difficult. In our recent work, we asked what the benefits and disadvantages of digital tablet-based data collection over paper for the in-hospital HD population are, developing and evaluating with multidisciplinary experts and patients in the NHS Greater Glasgow and Clyde health board.



Methods

Our work was carried out in two stages: (1) iterative development cycles with a multidisciplinary group of experts (senior academics, surgeons, nephrologists, etc.) and (2) implementation and evaluation within HD treatment. After 6 weeks, of using the portal on a tablet during regular treatment, evaluations were completed afterwards using the System Usability Scale (SUS) and feedback through interviews. We also interviewed the clinical research fellow delivering the portal and assisting patients during the study, to elicit their observations and experiences of paper and digital data collection.

Haemodialysis patients preferred tablet-based input vs paper for quality-of-life data collection.

Tablets overcame situational impairment and promoted patient independence and sense of privacy.

Efforts must be made for maintaining perceived value and engagement and knowing when to offer conventional alternatives where appropriate.



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Results

After 33 meetings with n=7 experts and iterative development cycles over, the refined patient portal was deployed. In total, n=26 patients completed SUS evaluations and n=19 patient interviews were held, as well as one with the clinical research fellow. Thematic analysis was conducted via the framework method and produced six themes about using the patient portal to complete QoL measures, alongside design requirements for future work.

I think it's easier to place a tablet on your legs and use a pen or stylus, even with your non-dominant hand, you can do that...

Awkward because in dominant hand but much easier than writing - difficult to add written comment with non-dominant hand...

Patients overwhelmingly preferred the digital to paper. Both patients and the researcher reported it was easier to use the tablet during HD than complete a paper form, especially where patients are unable to use their dominant arm as it is being used for cannulation. Automatic validation and storage of data streamlined data collection for the researcher and gave patients a sense of privacy, able to give honest responses about their care and a sense of independence.

...I don't like bringing things up myself. I don't talk about it much.

I like being left to complete it. I feel I can be more honest than if I am asked a question directly.

However it was also clear from interviews and the literature that traditional alternatives should be provided for those who may be inexperienced or unwilling to use technology. Perceived value of such systems is also key to their success and must be maintained, otherwise patients will see no benefit to engaging.

I communicate with nurses/doctors when I need to. I am also quite able to understand what is being said to me when discussing my health. feel I am perfectly able to