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CFHealthHub: Development and evaluation of videos incorporating peer description of successful self-management with inhaled therapies in adults with CF used to build self-efficacy to support self-care within the CFHealthHub complex intervention

Objectives: CFHealthHub (CFHH) is a complex intervention to help people with cystic fibrosis (PWCF) master self-care. Self-efficacy is an important determinant of behaviour change and peer modelling of success can increase self-efficacy.

Methods: We recruited adult PWCF from five UK CF units. Those post lung transplant, on the active transplant list or in the palliative phase of disease were excluded. Participants were purposively sampled based on objectively-measured adherence; lung function and socio-demographic characteristics. Video interviews were conducted in participants' homes by the Health Experiences Research Group from the University of Oxford. Semi-structured interviews explored patients' experience of CF and barriers and facilitators of nebuliser adherence. Interviews were analysed thematically using NVivo 10, within the COM-B model and then reviewed to select video clips for inclusion on CFHH with participant consent.

Results: Fourteen interviews were conducted between October 15 and August 16. PWCF described experiences of using inhaled therapy, motivations to improve adherence, and strategies for mastery. Initial qualitative research conducted in the CFHealthHub pilot suggested that overall the videos were well received. Some PWCF shown videos to support self-efficacy in the pilot RCT had concerns that seeing videos of PWCF who were healthier might make them reflect negatively on their comparative status and videos of PWCF who were less healthy might create anxieties about future health decline.

Conclusion: We have developed 'talking heads' videos to support behaviour change as part of a complex intervention. Some but not all PWCF found the videos helpful. It is important to sensitively support choice in the resources provided to PWCF aiming to increase self-efficacy.

Patient and public involvement to inform complex intervention coproduction and evaluation in the CFHealthHub self-management programme

Objectives: The CFHealthHub (CFHH) program has co-developed a complex intervention to support self-management in CF. Patient and public involvement (PPI) is essential in the co-production and testing of complex interventions. Cross-infection risk prevents people with cystic fibrosis (pwCF) meeting face to face and PPI engagement must take this into account. We present our experience of using technology to establish and maintain PPI input over the first 4 years of the program.

Methods: PPI involvement started in 2013 during protocol development. The PPI group includes adults with CF and parents of pwCF, chaired by the programme's PPI Lead (also a pwCF). Various strategies identified the PPI team - a leaflet distributed by participating CF units; listing of the involvement opportunity on the People in Research website; and direct approach from the PPI Lead to pwCF within the local area. Regular teleconferences allowed feedback on progress and ensured that PPI members felt part of the program. Teleconferences were kept short to reduce burden (approximately one hour).

Results: Teleconferences occurred approximately every three months. Topics included methods of participant contact, form and content of CFHealthHub, data security and consent plans within the data observatory. The PPI input complemented process evaluation carried out within the trial and shaped co-production of the CFHH website. On occasions teleconferences were supplemented by email communication between visits. Over 4 years some PPI members dropped out as personal circumstances changed and replacements were recruited.

Conclusion: Complex intervention development and evaluation requires PPI input over a period of years. We have found that a multifaceted approach to recruitment and involvement has allowed sustained input over 4 years which has allowed pwCF to shape intervention development and trial procedures.

Evaluation of the training programme to deliver a complex intervention supporting self-management with inhaled therapy in Adults with CF.

Objectives: A key domain of fidelity relates to the assessment of training. The aim was to evaluate a training programme for interventionists delivering a complex intervention to support increased nebuliser adherence in adults with CF.

Methods: In the pilot study which started in 2016 training was completed by three interventionists from two CF centres. Phase 1, training: 2 day group face to face training: included underpinning theory, study design and the CFHealthHub (CFHH) digital platform. An evaluation questionnaire was completed at the end of Phase 1. Phase 2 training: 5 week online training using a Virtual Learning Environment: included weekly tasks supplemented by weekly teleconference tutorials. A case study assessment was completed at the end of Phase 2. In phase 3 interventionists submitted an audio recording and study documents relating to delivery of the first intervention session within the pilot RCT. These were assessed for fidelity using standardised checklists. Semi-structured interviews were conducted by a qualitative researcher with all interventionists to obtain feedback about training quality and suggested improvements.

Results: The evaluation questionnaire found confidence ratings were high (>7/10) for intervention delivery following training. Fidelity assessment for the first intervention delivered within the pilot RCT trial found good adherence to content but variable levels of quality of delivery. Interventionists found training to be useful but identified some changes to training content to support how they used CFHH.

Conclusion: Fidelity assessment identified some issues in the delivery of the intervention, combined with the feedback from the qualitative research this allowed revisions to training for the main trial. This study emphasises the need for thorough training, certification of interventionists and fidelity assessment within complex interventions.

The ECSF organising committee asked us to place 3 abstracts on one poster and this is why this poster has the format above.

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