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Evaluation of providing patient online access to electronic health care records (EHR) in cystic fibrosis

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Introduction: In the UK, patient online access to healthcare records (EHR) is now a national requirement. The aim of this study was to evaluate the feasibility, benefits and acceptability to patients of providing secure access to their hospital EHR, and explore technological usability and patient satisfaction.

Methods: In this 6 month RCT, 100 adult patients with CF were randomised after completing baseline questionnaires (GAD-7, PHQ-9, CFQ-R, PAM-13, SEMCD, PEPPI, DMI-CF, perceptions of and intention to engage with patient access, computer literacy, medication accuracy) to receive EHR access (Active n=50) or usual treatment (Control n=50). The active group had access to diagnosis, medications, test results and consultations. Questionnaires were repeated at 6 months; active group also completed SUS, PHWSUQ, perceptions of patient access and engagement.

Results: To date, n=90 have completed the study (Active n=44, 21 male, mean age 29.0±10.1 yrs; Control, 29 male, mean age 29.2±9.7 yrs). At baseline, there was no difference between groups except social and emotional functioning (CFQR), which was higher in the active group ($p<0.05$). Patient access had no effect on anxiety, depression, confidence and engagement in healthcare, overall quality of life, trust and interactions with staff, and computer literacy. Over 6 months, perceptions of health increased in the control group and remained unchanged in the intervention group ($p=0.02$). Quality of life scores for social functioning and digestive symptoms decreased with the intervention and remained unchanged in the control group ($p=0.001$ and $p=0.04$). Patient access scored above average for usability, 84% satisfaction, 73% ease of use and 78% usefulness. In the active group, 98% agreed that access was still a good idea (n=1 was undecided), and 100% want to continue having access. Patients agreed that they understood CF better (85%), and that information was easy to understand (82%) and more helpful than confusing (90%). There were no privacy or security concerns in 95% and 92% of cases.

Conclusion: Access to EHR does not appear to have a negative effect and uptake by patients has been very positive. Full data will be presented.