TrueColours Ulcerative Colitis (TCUC): Will patients with UC complete digital questionnaires in real-time?

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BACKGROUND

TCUC is a comprehensive real-time web-based programme for UC patients. It monitors multiple parameters via electronic questionnaires: symptoms, quality of life (QoL), and outcomes (eg hospitalisation). Medications are entered and personalised treatment guidance formulated. This information, graphically displayed on a traffic light system, is available to the patient and clinical team via the TCUC website (<https://ouh.truecolours.nhs.uk/ibd/en/>), and is housed on a secure National Health Service server. The objectives were to assess feasibility, usability and adherence of TCUC.

METHODS

A prospective, non-randomised 6-month pilot study recruited patients from the Oxford Inflammatory Bowel Disease service. Recruitment and retention rates were calculated. Questionnaires were scheduled either daily (simple clinical colitis activity index, SCCAI), fortnightly (QoL, IBD-Control-8, CUCQ-8 and EQ5D-5L), or once only (outcomes, www.ichom.org). Patients received email prompts linked to scheduled questionnaires. Monthly home faecal calprotectin measurements were incorporated, monthly blood tests collected and flexible sigmoidoscopy performed at entry and after 6 months. Usability was assessed via the System Usability Scale (SUS) (n=59) as well as qualitative interviews (n=28).

RESULTS

Recruitment rate was 66/240 (28%). Retention rate was 57/66 (86%). Of 66 patients, 29 (44%) were male, median age 41 yrs (IQR 17.0), median duration of disease 5.6 years (IQR 10.7), distribution of disease (E1 18%, E2 38%, E3 33%, unknown 11%), activity of disease at entry (remission 38%, mild 35%, moderate 26%, severe 1%), tertiary education 58%, biologic use 47%. Adherence to daily SCCAI questionnaires: 76%, fortnightly QoL questionnaires: 95%, and ICHOM: 100%. Uptake of faecal calprotectin home testing was 73% (48/66), median tests 4 (IQR 3). Median SUS score was 92.5 (IQR 15). Qualitative interviews confirmed that TCUC was efficient, effective, and easy to learn. Improvements suggested were optimisation of the graphical display on smartphones and decreasing the number of QoL questionnaires from three to one, with a preference for IBD-Control.

CONCLUSIONS

Patients with UC will collect digital data in real-time, with good adherence to symptom, QoL, and outcome questionnaires as well as faecal calprotectin home testing. Usability was classified as 'superior' but further improvements are possible. Larger studies are required to determine cost effectiveness.