Introduction Patients with neuroendocrine tumours (NETs) have significantly worse health-related quality of life (HRQoL) than the general population. Technological advances have significantly increased electronic patient-reported outcome (ePRO) data collection capabilities. Currently, there is little longitudinal PRO/ePRO data and limited data on gastrointestinal symptoms, particularly ‘diarrhoea’, in NET patients.

Methods 12 patients with NETs were given a tablet installed with the CABARET application (app). Using the app patients recorded bowel movements according to Bristol Stool Chart (BSC), completed a weekly gastrointestinal (GI) symptom survey and an EORTC QLQ-GINET21 survey (for QoL) every 2 weeks. Data inputted to the app was accessible to clinicians via a secure method linked to hospital records. 5 months of user input was analysed to assess trends. App usability was evaluated via a patient questionnaire.

Results There was a significant (p<0.01) correlation between GI symptom burden and QoL. Symptoms varied over time: the coefficient of variation in individual patients for urgency was 86% overall and up to 40% for BSC. Type 6–7 stool made up 57% of all reported with only 1.1% of stool being type 1–2. Lethargy, flatulence and bowel urgency were found to most affect patient’s lives, whilst worries about future health and effects on family members were the most frequent concerns reported. 91% of patients found the app easy to use.

Conclusions The app appears to be a patient-friendly method of acquiring real-time, detailed longitudinal data on NET symptoms and QoL, potentially allowing earlier recognition of symptom change and intervention. GI symptoms can vary over time suggesting a ‘snapshot’ view may not be truly reflective. Further work is required to assess the impact on patient management on a wider scale.