Oxford AHSN case study

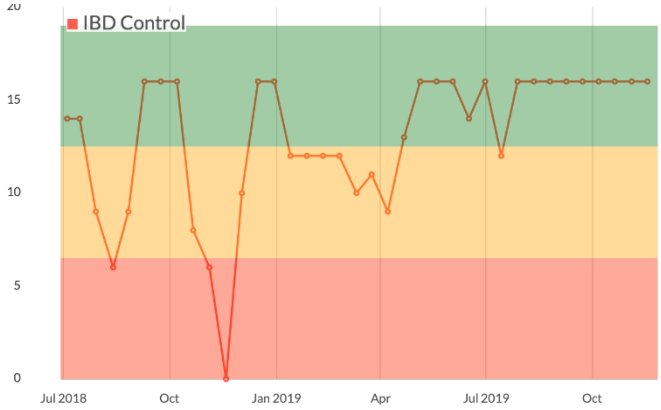
Date: Q2 2020/2021

Programme / theme: Strategic and Industry Partnerships

Title: Real-time data collection supports patients with Inflammatory Bowel Disease through Oxford AHSN-IBD, the UK's first independently funded IBD network.

Overview Summary

The Oxford AHSN Inflammatory Bowel Disease (IBD) Network has successfully introduced real-time data collection through a web-based system into clinical care for patients with ulcerative colitis or Crohn's disease. Over 1600 patients now record symptoms (daily or weekly), quality of life (fortnightly) and internationally agreed patient reported outcomes (PROMs, quarterly), through validated indices. It is set to be established in Winchester (Wessex AHSN) and become the pilot project for patient-entered data into their electronic health record in Oxford. The True Colours system was a finalist in the national BMJ Awards for Digital Innovation in 2019.



Oxford AHSN-IBD was the UK's first independently funded IBD network. Partners include AbbVie (international PROMs (www.ichom.org), led from Oxford); the Norman Collisson Foundation (creation of TrueColours-IBD from a Psychiatry template); Takeda (introduction to clinical practice); Janssen (operational management). Oxford AHSN coordinated operational management and acted as an interface between industry and clinical practice.

The system is now established to monitor patients with chronic disease in real time. Mathematical modelling of responses is used to inform the need for a clinic appointment, with appointments deferred if appropriate, early identification of relapse and prospective documentation of outcomes. It has come into its own for remote monitoring during the pandemic.

Challenge/ problem

- The problem: The goal of treating IBD is to improve patients' quality of life (QoL) and outcomes, but an excess of demand over clinic capacity means that neither are measured in practice
- No system exists for measuring QoL or outcomes, making it impossible to benchmark care. Local waiting times prevent a responsive service

- People affected: IBD most commonly presents in young adults, lasting for life. Causes remain unknown and there is no cure. Flares of disease impair quality of life (QoL). Over 500,000 people in the UK are affected, costing >£500 million/year, excluding societal costs
- Why unaddressed: Conventional, hospital-based follow up is dictated by clinic capacity, while QoL and outcomes depend on healthcare professionals to enter data. Up to 62% of scheduled appointments do not result in any change in therapy
- The solution is for patients to enter their own data using validated indices and manage clinic capacity accordingly

How is the AHSN involved?

Oxford AHSN provided a pivotal interface between industry support and clinical practice. The interests of industry (through medical education grants), clinical and research teams were protected by managing funding through a third party. Oxford AHSN provided project management skills and brokered connections to data privacy impact assessment, ethical evaluation, timelines and goals. Partners include AbbVie (international PROMs www.ichom.org); the Norman Collinson Foundation (creation of True-Colours-IBD from a Psychiatry template); Takeda (introduction to clinical practice); Janssen (operational management) and funding leveraged to date is in excess of £1million.

Impacts and outcomes of the AHSN involvement to date

In the first 500 patients enrolled (2017-19, 401 UC, 99 CD), ICHOM outcomes quantified prednisolone use for >3 months (13%), at least one hospital admission in the preceding year (16%), and emergency department presentation (20%). There were high rates of fatigue (53%) and mood disturbance (26%). These patient-reported data quantify the deficits in current care and act as a benchmark against which other centres can compare outcomes. The Get It Right First Time (GIRFT) initiative for IBD by NHS England (2019), commended IBD care in Oxford for halving the hospitalisation rate, despite having one of the largest patient cohorts in the country.

The Escalation of Therapy of Intervention (ETI) calculator from TrueColours responses identified 62% of scheduled appointments that could potentially be deferred. Deferring a third of these (20%) with patient agreement saves 500 appointments/year (£45000) in Oxford alone, increasing capacity for urgent appointments. The process was established in Oxford during the pandemic, resolving the need for an NIHR-supported trial (Project RAINBOW) to demonstrate the economic value of remote, digital monitoring.

Qualitative analysis through user interviews to data saturation identified core themes from using TrueColours: awareness, control, decision-making, reassurance, communication and burden of treatment, with a transcending theme of patient empowerment.

Barriers to adoption beyond Oxford include data sharing agreements, integrating patient-entered data onto ePR, bandwidth of hospital IT and computer scientist support for infrastructure. All are in the process of being resolved and data control will migrate from Oxford Health to Oxford University Hospitals.

Supporting quotes

Innovator

The Oxford AHSN first provided the vehicle for establishing patient-reported outcomes in ulcerative colitis and Crohn's disease, then helped develop real time data collection from patients that has now translated into daily clinical practice. It was exciting setting up the first independently funded AHSN clinical network in the country and the infrastructure support, panning and project management from Oxford AHSN were pivotal to success.

Professor Simon Travis, Translational Gastroenterology Unit, Oxford University Hospitals

AHSN

We have successfully managed and implemented the ICHOM set of standards for patients with Inflammatory Bowel Disease. Patients are now able to record their Patient Reported Outcomes data on the real-time web-based platform TrueColours in Oxford. High adherence rate (84%) demonstrated feasibility and capability of the TrueColours platform.

Marianna Lepetyukh, Oxford AHSN

Plans and timescales for spread and adoption

Next steps include

- Development of InSpectrum, a multimodal analytic tool for patient-entered data, to allow an instant ('real time') overview of disease activity of the patient population for clinicians (nurses, allied professionals and doctors)
- Integration of the ETI Calculator to outpatient bookings
- Extension to other Trusts
- Migration of data control from a secure server in Oxford Health, to Oxford University

TrueColours is the quintessential Patient and Public Involvement and Engagement (PPIE) collaboration: patients are central to the process and patients are part of the development team. The system demonstrates that it is possible to record healthcare-relevant data through validated PROMS in real time (emergency department visits, hospitalisation, steroid-dependency, disease activity, anaemia and other measures, www.ichom.org) which Commissioners can use to benchmark IBD services and document changes in quality of care.

Start and end dates

Q2 2015-Q2 2020

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