



Event summary:

Crohn’s Disease and Ulcerative Colitis public information event: The changing face of Inflammatory Bowel Disease – Progress in research and clinical care

21 March 2023

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Event synopsis

292 members of the public and health professionals attended this event to hear the latest updates on the research, care and support available to people with Crohn’s and Colitis in Oxford and beyond.

The meeting was held as a hybrid event – 100 people attended in person at the John Radcliffe Hospital, Oxford and 192 attended online through Teams.

At the venue, information stalls were set up for attendees by the Clinical Trials Unit (Translational Gastroenterology Unit, University of Oxford), CICRA, CCUK, TrueColours, Translational Gastroenterology Unit Biobank, Oxford University Hospitals NHS Foundation Trust’s Here for Health and Membership teams, Royal Berkshire NHS Foundation Trust’s Gastroenterology team.

Introduction

Professor Jack Satsangi, Lee Placito Professor of Gastroenterology, Translational Gastroenterology Unit, Nuffield Department of Medicine, University of Oxford

It is estimated that by 2030, one in one hundred people in the UK will have Crohn’s or Ulcerative Colitis which are now common conditions. In the 21st Century several new therapies have been licensed for use, with more under development in clinical research trials.

The aim of research and clinical practice is to help achieve remission from disease, restore quality of life and to avoid complications caused by the disease or treatment itself. A key research goal is to identify the causes of these diseases, allowing prevention and cure.

The connections between genetic and environmental factors are being studied. Personalising care is now one of the standards of IBD UK, a partnership of organisations including the Royal College of Physicians, the Royal College of General Practitioners and Royal College of Nursing, CCUK and CICRA. This aims to give patients choice over their treatment, following discussion with their clinician.

Introduction to Crohn's and Colitis UK

David Lee, Network Treasurer, Crohn's and Colitis UK (CCUK) Oxfordshire



David talked about his early diagnosis with Crohn's disease as a young person and the care he has received. He explained that Crohn's and Colitis UK (CCUK) aims to improve quality of life for the estimated 500, 000 people in the UK who have the conditions.

The charity provides a range of information, from detail on Crohn's disease and Ulcerative Colitis and advice on managing symptoms to a guide on employment and IBD for employers. It funds high quality research to help achieve early and accurate diagnosis, and funds sustainable care services.

The charity also runs awareness raising campaigns and holds member's meetings. The Oxfordshire branch of CCUK has 500 members and is keen to hear from anyone who may be interested in getting involved with its work, and particularly those who may be interested in joining the organisation team.

For more information please contact: oxfordshire@networks.crohnsandcolitis.org.uk
Membership costs a small fee, find out more and sign up at www.crohnsandcolitis.org.uk

Introduction to Crohn's in Childhood Research Association (CICRA)

Sarah Brown, CICRA member



Sarah explained that CICRA is a UK charity which funds research projects to find better treatments for children with Crohn's and Colitis, supports children and families and works with health professionals to improve care and raises awareness of IBD in childhood.

Sarah described her family's experience when one of her children was diagnosed with IBDU (IBD Unclassified), and how CICRA helped. CICRA offers resources and services, including family information

days across the UK, information for schools, emotional wellbeing toolkits, resources for children and parents and help with transition from child to adult services. The charity also has an e-pals scheme so children can support each other.

New members are very welcome. Find out more and sign up on the website: www.cicra.org.

The Clinical Trials Facility (CTF) Experimental Medicine Division, University of Oxford

Dr Lulia Al-Hillawi, Heather Woodley, Research Nurse



Dr Lulia Al-Hillawi introduced the CTF Clinical Trials Team at the University of Oxford, based at the John Radcliffe Hospital. The experienced team conduct multiple research trials each year. Lulia and Heather thanked everyone who has taken part in a clinical Trial.

If you are patient who is being treated in Oxfordshire, and you are interested in finding out about gastroenterology clinical trials you may be able to take part in, please contact the CTF Clinical Trials Team by email at ctf.researchnurses@nhs.net

My experience of taking part in research

Alan, Patient/public representative



Alan, who has had Ulcerative Colitis for 50 years spoke of his experience of living with the condition and taking part in two clinical research trials. He said that for one of the trials he needed to be just ill enough to fit the criteria for the study, but no more.

Alan found taking part in research to be a positive experience, with regular full check-ups, and phone or email contact with the team regarding any concerns. Since being on one new treatment in trial, his IBD flare ups have decreased, and he encouraged others to consider joining clinical trials if possible.

New therapies in inflammatory bowel disease (IBD)

Dr Oliver Brain, Consultant Gastroenterologist, Oxford University Hospital NHS Foundation Trust



Dr Oliver Brain explained that understanding the immune system in the gut has been key to developing new drugs for IBD.

He explained that the gut is a balanced ecosystem of bugs, viruses, fungi and immune cells and food. The immune system is ready to respond with an inflammatory response to kill infections. In IBD the mechanisms within the gut do not work as they should, and inflammation can persist longer than needed. Infections may also persist.

Since 2016 a number of new drugs termed 'Advanced therapies' have become available, for example Upadacitinib for Crohn's and Filgotinib and Ozanimod for Ulcerative Colitis. These new drugs work by acting on cells in the gut in different ways.

These add to the more established drugs in use today e.g., steroids, Anti -TNFs. These may not be effective for everyone/ the effectiveness may decrease over time. More research is needed to help determine which of the new drugs are most effective in any given person, and which can be combined. Teams in Oxford and worldwide are working on developing tests to discover biomarkers so that a biopsy or blood test can be used to determine which treatment is best to use for each patient. Dr Brain thanked everyone who has taken part in research studies which are critical to improving treatments and care.

Accessing IBD Treatments

Sarah Cripps, Consultant Pharmacist, Gastroenterology/Hepatology, Oxford University Hospitals NHS Foundation Trust



Sarah Cripps works as part of a team of pharmacists at the John Radcliffe Hospital. She explained that drugs are administered to patients following market approval, following guidelines for monitoring and governance. IBD admissions have more than doubled in the ten years to 2013. Often patients will take a range of drugs over time. The aim of treatment is to induce and maintain remission with the safest and most cost-effective treatment.

Advanced therapies are the biggest cost pressure for the NHS alongside admissions, prescribed only through hospitals. Pharmacists follow national and international guidelines and work closely with Clinical Commissioning Groups which commission and pay for treatments, and clinicians. Homecare is used by the NHS to deliver high-cost medicines to patients, with no prescription fees.

When selecting treatments for patients pharmacists and clinicians consider the site, extent and severity of the disease and other factors. Thorough patient checks are made before the first dose is given, with follow up blood tests.

The True Colours IBD Programme

Dr Alissa Walsh, Consultant Physician, Department of Gastroenterology, Oxford University Hospitals NHS Foundation Trust



Dr Alissa Walsh explained how TrueColours supports the personalised approach to patient care, through using patient reported outcomes to inform decisions about treatment. Oxford is the first centre in the world to gather longitudinal data in this way through repeated observations.

TrueColours is a web-based programme that gathers information through email prompts to patients. Clinicians and patients can look at the patient's data in TrueColours, displayed in graphs. The system has received excellent usability ratings. Patients have said that the system gives them reassurance and helps them feel more in control of their condition.

The ETI (escalation of therapy/intervention) calculator has been designed to predict the need for urgent intervention based on reported symptoms and quality of life. The Oxford University Hospitals NHS Foundation Trust pharmacy database is currently being linked to TrueColours. There are plans to expand TrueColours to include children from aged 12+, other health conditions and patients outside Oxford. Alissa encouraged patients who can join TrueColours to do so.

Diet and IBD: Progress at last

Dr Miranda Lomer, Senior Consultant Dietician in Gastroenterology, Guy's and St Thomas' NHS Foundation Trust (pre-recorded talk)



Dr Miranda Lomer has worked in Crohn's and Colitis since the 1990's and wrote the British Dietetic Association diet and IBD guidelines in 2022. Her talk covered diet as a cause of IBD and dietary management for people with Crohn's or Colitis. She recommended CCUK's website as a good reference. Dietary changes can be a trigger for IBD, alongside genetics and changes in the immune system.

Miranda talked about many aspects of diet including processed meat, food additives, the Eatwell Guide, recommendations regarding fibre intake, the FODMAP diet, the Mediterranean diet, exclusive enteral nutrition as an option for Crohn's disease and diets being developed to treat active disease in Crohn's and Ulcerative Colitis.

A systematic review comparing the results of multiple studies in 2023 found a link between consuming ultra-processed foods which contain food additives and little intact food and development of Crohn's Disease. There is a need for more studies looking at diet. Finally, Miranda recommended that patients speak to their clinician/dietician before changing their diet.

Panel question and answer session and conclusion

During the Panel Q&A session, questions were answered on a range of topics including food intolerance tests, fibre intake, particular diets, treatments when receiving therapy for cancer or during pregnancy for people who have Crohn's or Colitis.

Professor Paul Klenerman gave the closing words, highlighting that Oxford is part of the global movement aiming to improve the way Crohn's and Colitis are treated and ultimately find a cure.

Feedback on the event

Feedback from the audience after the event was generally positive with praise for all the presentations and panel question and answer session. New treatments and diet received a particularly high number of mentions.

Organisation

This event was organised by the Translational Research Group, Nuffield Department of Medicine, University of Oxford, charities Crohn's and Colitis UK (CCUK) and Crohn's in Childhood Research Association (CICRA), the National Institute for Health and Care Research (NIHR) Clinical Research Network Thames Valley and South Midlands, and the NIHR Oxford Biomedical Research Centre.

We are grateful for the support of all the organisations and individuals who have helped us promote and arrange this event, and to everyone who attended.

NIHR | National Institute for
Health and Care Research



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Oxford University Hospitals
NHS Foundation Trust

cicra 
better lives for children with crohns and colitis

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COLITIS UK** 
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