

Winter 2019

York IBD Matters

IBD Patient Education Evening & Patient Forum

Our next patient education evening will be in November and will be held the Friargate Quaker Meeting House in York. There will be a number of talks from our Gastroenterology team including Professor Veysey, dieticians and the IBD nursing team. Check our Facebook page for more information nearer the time.



The nearest car park to the meeting house is Clifford's Tower. Parking cost is £2.00 after 6pm or free to city of York discount badge holders

Have you had your say?

IBD UK is a partnership of 17 patient and professional organisations working together for everyone affected by Inflammatory Bowel Disease they have come together to develop and publish new standards that define what good care should look like for people with IBD.

The IBD Standards say what high-quality care should look like at every point of the patient journey - from first symptoms, to diagnosis, treatment, and ongoing care.

The aim of the IBD standards is to remove the variation in care and ensure that people with IBD receive safe, consistent, high - quality, personalised care, whatever their age and wherever they live in the UK.

By sharing your experiences in the IBD Patient Survey you will highlight how York Teaching Hospitals NHS Trust is doing, and how they could improve your care. You can make your voice heard and complete the new UK-wide IBD Patient Survey to help your IBD team give you the best possible care.

Complete the survey before it closes on the Friday 22 November 2019 to ensure your voice is heard by accessing <https://www.ibduk.org/ibd-patient-survey> or call Crohn's & Colitis UK on 01727 830 038 to request a paper copy of the survey.



New Endoscopy Unit opens



A FLAGSHIP £10 million new endoscopy unit - one of the largest and most modern of its kind in England is now open at York Hospital.

The unit, which has taken just 18 months to complete, will increase capacity to meet the growing need for endoscopic investigations nationally and is expected to provide around 15,000 treatments each year.

The new unit is a two-storey building, with seven endoscopy procedure rooms on the first floor, one equipped with radiology facilities.

It also has plant rooms, staff changing facilities, meeting rooms, and a seminar room with direct audio-visual links to the endoscopy rooms, to allow live streaming for training.

The clinic will be led by a team of consultants and supported by healthcare professionals. Srinivas Chintapatla, consultant surgeon and care group director, who has been instrumental in the design, development and build of the new unit, said: "The new unit, one of the most modern and largest endoscopy units in the country, is an exciting development for the trust.

"We used to do endoscopy in three rooms, so moving to a seven room unit will deliver significant improvements to diagnostic and therapeutic endoscopy waiting times and increase the range of procedures offered.

"In the new unit we will be using advanced technology, like endoscopy simulators, and we will be introducing new procedures like transnasal endoscopy, which means that patients having a gastroscopy will be more comfortable.

"The unit will allow us to teach and support the next generation of nurse endoscopists to develop their skills and we will also be in a position to hold courses to teach endoscopy which will raise the profile of the unit nationally."

The facility was officially opened by Michael Proctor, former chief executive of the trust, who was integral to the new build.

He said: "I'm delighted to return to the trust to officially open the new endoscopy and gastrointestinal physiology unit. It's truly fantastic to see a unit that is 100 per cent designed around patients' needs and complements their flow through the department. It's bright and spacious, offering patients the best possible environment. I'd like to congratulate everyone involved." The new flagship unit, built above the hospital's existing physiotherapy department, has been designed to increase capacity to meet growing demand, improve the efficiency of patient flow and enhance the patient experience. Simon Morrith, chief executive, York Teaching Hospital NHS Foundation Trust added: "This is one of the biggest capital investments for many years and will allow the trust to provide clinical services to a growing number of patients needing an endoscopy.

"This is an exciting development for the trust and it will transform our service into a center of excellence for endoscopy, providing an enhanced high quality care to our patients."

The unit is part of the trust's continued investment in its hospitals. Earlier this month the trust submitted plans for a new flagship vascular imaging unit for York Hospital to provide enhanced diagnosis and care.





If you're taking an immunosuppressant, or a biological drug then it is important that you have an annual flu vaccination as you're at a greater risk than the general population from the flu.

Influenza is characterised by the sudden onset of constitutional and respiratory symptoms typically with fever.

In most cases, the diagnosis is based upon symptoms and knowledge of the local active prevalence of influenza infection.

The influenza vaccination works by making the patient slightly ill with the influenza virus, allowing their immune system to build a defence against the virus and therefore destroy it on subsequent (real life) exposure.

Many persons with IBD take immunosuppressive agents to reduce their symptoms.

While taking these medications, the patient's immune system capabilities are diminished, which increases their chance of infection. Therefore, immunization could cause concern for those who have compromised immune systems, fearing that they might be unable to fight off the initial exposure to the vaccine.



The LUCID Study

At the recent United European Gastroenterology (UEG) Week, data was presented from more than 1600 people with Ulcerative Colitis, from 10 countries across Europe. The results highlighted the impact on quality of life, work and productivity for people living with condition.

The study, called LUCID (Living with Ulcerative Colitis: Identifying the socioeconomic burden), which was undertaken by the University of Chester and the Economic research group, HCD Economics in partnership with Crohn's & Colitis UK, showed that two thirds of people with Colitis experience pain and discomfort and over half have experienced anxiety and depression due to their condition.

LUCID included data from a number of different hospitals across Europe. The study was observational, which means the researchers reviewed a group of people living with Colitis, without changing anything about their treatment or care. This included collecting information from patients through questionnaires and surveys and matching it to clinical records completed by the patients' consultants.

This study also describes what is most important to people living with Colitis, based on the information they gave about the social, economic and quality of life impact of their condition.



Helen Terry, Director of Research, at Crohn's & Colitis UK explains that "these important first findings from the LUCID study highlight both the mental and physical impact Colitis can have on people living with the

condition. We are grateful to everyone who took part in the study. Their support means we have even more evidence to demonstrate how debilitating Colitis can be. We're looking forward to seeing the full results published next year."

The purpose of the LUCID study was to evaluate the current burden of Ulcerative Colitis across ten European countries including the EU5 (UK, France, Germany, Italy, Spain) and Norway, Denmark, Romania, Poland and Turkey.

The primary objective was to measure the socioeconomic cost of Colitis including direct medical, direct non-medical and indirect costs. The secondary objective was to explore the impact of Colitis on patients' quality of life and work productivity.

Wetherspoons install Not Every Disability is Visible toilet signs

Major pub chain JD Wetherspoon will install new signage on all its accessible toilets to help stop stigma and discrimination towards people with hidden illnesses such as Crohn's disease and ulcerative colitis.

A major anxiety for people living with a lifelong health condition, like Crohn's or Colitis, is being confronted about why they are using the accessible toilets they urgently need.

A survey by Crohn's colitis UK revealed that half of people with Crohn's or Colitis said they have felt prevented from going to restaurants (49%) and pubs (43%) because they fear discrimination. Whilst someone may look 'okay' on the outside, they may crucially need to use the accessible toilets, due to symptoms such as urgent and frequent diarrhoea.

JD Wetherspoon is the first pub chain to change their accessible toilet signage in response to the CCUK campaign. Following an incident recently where a young woman, Amber Davies, was confronted by staff at a JD Wetherspoon pub for using the accessible toilets, the company is taking a positive step to end the stigma experienced by people living with invisible disabilities.

Eddie Gershon, a Wetherspoon spokesman said "want to make sure all of our customers feel comfortable when visiting any of our pubs. We're delighted to install these new signs that help to both increase awareness that not all disabilities are visible, and to ensure that anyone who needs to, can feel confident using our accessible toilets."



Over 80% of people with Crohn's or Colitis said they feel more comfortable visiting places with the Not Every Disability is Visible signs installed, powerfully demonstrating that these signs have a real impact on people's lives.



Argos supports those with IBD by training staff to recognise the 'Can't Wait Card'

Argos is the latest retail company to show its guts by working to ensure that any visitor who shows their Can't Wait Card in one of their 800 UK stores will be able to access staff toilets.

Argos have shown support for the Crohn's & Colitis UK Not Every Disability is Visible campaign, however as their stores do not have public-facing toilets, they are training staff to ensure they understand and assist those who need urgent access to toilets by showing them to their employee facilities.

Sandra Wilkinson, Customer Experience Manager at Argos said "Argos is a proud supporter of Crohn's & Colitis UK. Our group vision is to be the most inclusive retailer and we recognise that some customers often need to use a toilet, without delay. Together with our colleagues, we welcome the use of our facilities in store."

Argos is part of the Sainsbury's Group, who have already shown their support for the campaign by installing Not Every Disability is Visible signage on their accessible toilets. They have also implemented the Sunflower Lanyard campaign, first introduced by Gatwick Airport, to allow staff to more easily recognise and support customers with hidden illnesses.

"Argos is giving their very welcome support to many thousands of people with debilitating and chronic health conditions such as Crohn's or Colitis; their help - along with other national retailers - will reassure many people and support them to shop more confidently while helping to tackle the stigma of toilet urgency."

Dan McLean, Director of Marketing, Communications & Membership at Crohn's & Colitis UK

Visit our website: - www.yorkhospitals.nhs.uk/our-services/a-z-of-services/inflammatory-bowel-disease/

Find us on Facebook: - York IBD Services

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