

Winter 2018

York IBD Matters

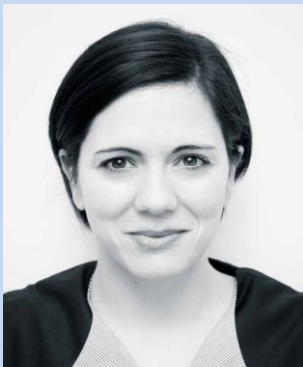
IBD Patient Education Evening & Patient Forum

Our next patient education evening will be in April and will be held the Friargate Quaker Meeting House in York. Check our Facebook page for more information nearer the time. At the last meeting Dr Gerry Robins gave a very informative talk about the role of endoscopy in IBD and Dietitian Carmen Nusco spoke about diet in IBD.



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

Clinical Doctorate Fellow in Nursing, Sara Ma joins the IBD nursing team.



Sara joined the team in October 2018 as York Teaching Hospitals first Clinical Doctorate Fellow in Nursing. She will be joining the team three days a week as an Inflammatory Bowel Disease Specialist Nurse. The rest of her time will be divided between the

University of York and York Hospital undertaking a PhD in Inflammatory Bowel Disease.

Sara trained and worked as an Intensive Care Nurse in London and joined York Teaching Hospital five years ago as an Anaesthetics and Critical Care Nurse.

Sara completed her Masters in Nursing in 2017, investigating whether preoperative brain natriuretic peptide is predictive of post-operative cardiac risk. Between 2015 and 2018, she was involved in the set up and running of a new Perioperative Medicine

Service at York Hospital working with patients undergoing major elective colorectal surgery.

The CARDINAL network (Clinical Doctoral Nurses and Allied Health Professionals) is a new initiative between hospitals and universities in the Yorkshire and Humber region. It aims to increase the number of Nurses and Allied Health Professionals undertaking further academic research.

Supervised by Professor Veysey and also Professor Ersser who is based at the University of York, Sara is interested in improving IBD care through the development of patient-centric needs assessments and care pathways that evaluate psychosocial aspects of a patient's health. She is particularly interested in the impact of IBD on sexual function.

If you are interested in what Sara is up to or want to find out more, you can email her on sara.ma@york.nhs.uk

You can direct future research



For the last 2 years, a group of healthcare professionals, including gastroenterologists, surgeons, specialist nurses, dietitians, radiologists and GPs have been creating up-to-date best practice guidelines for the management of Ulcerative Colitis and Crohn's disease in adults on behalf of the British Society of Gastroenterology (BSG). This important document will be published in 2019 and Crohn's & Colitis UK have represented patients as part of this.

The team at the BSG have undertaken a thorough review of published research and have identified 20 key areas where more clinical research is necessary to help patients and healthcare professionals better manage Ulcerative Colitis and Crohn's disease in 2019 and beyond. Whilst there is no guarantee that any particular area highlighted in the BSG guideline will receive more research funding, these research priorities can help to inform medical research charities, funding bodies and the government of where more research is needed.

A crucial part of highlighting priority areas for research is to understand their importance to patients.

To do this, Crohn's & Colitis UK, have created a survey and would like to invite you to take part by scoring the importance of each research topic. Average scores from this survey will be included in the final guideline publication in 2019.

If you decide to take part:

- This survey is anonymous, but it will ask if you are a patient, relative, friend or healthcare professional, your gender and age. You do not have to answer these questions if you don't want to.
- You will see 20 research topics. Each topic is presented as a question(s) that researchers want to find the answers to. For each one they would like you to rate the importance of this research topic by giving a score between 1 and 9 (where 1 is not important and 9 is very important).
- You can decide not to score any or all of the topics for any reason and do not need to give a reason for doing so. Please just skip the question and you can move on to the next.
- At the end of the survey there is an option to add your contact details to receive information about future research opportunities.

Examples of research topics are below:-

IBD is less likely to flare up later if the bowel is fully healed. Some patients have no symptoms, but evidence of inflammation is seen during colonoscopy or scans. In these cases, how acceptable is it to increase or change treatment to try and heal this inflammation? How successful and safe is this?

Some people with IBD are at higher risk of developing colon cancer. What is the best way to measure whether someone is at higher risk? What is the best way to prevent, diagnose, treat, or look for cancer, or early changes that might develop into cancer? How frequently should patients with IBD be assessed in this way?

Why do many IBD patients experience fatigue (tiredness not relieved by resting) and pain? What treatments (drugs or non-drug treatments) are best to help these symptoms? Why do these symptoms continue even if their Crohn's disease or Ulcerative Colitis are no longer active?

With an increasing range of biologic treatments available for Crohn's disease and Ulcerative Colitis, working out which are better suited for individual patients is more important than ever. How can doctors and other members of the healthcare team select the best treatment at the right time for each patient with IBD? Do some treatments work better or worse in patients with different types of IBD, or with different test results?

- This survey will take less 15 minutes to complete and closes on 14th January 2019.

New Chief Executive for Crohn's Colitis UK



Sarah Sleet is an experienced and successful Chief Executive and worked with a broad range of health and patient groups and European patient organisations, as well as government advisory and research bodies.

She has also built expertise in education, social and economic policy, scientific research, income generation and campaigning.

She lives in Oxford and is Chair of Community Christmas, a small charity working to alleviate loneliness at Christmas.

Can food cause or cure IBD?

Can food cause IBD?

Currently, there is no clear evidence that any particular food or food additive directly causes IBD.

However, some researchers think that there may be some sort of link between diet and IBD. One suggested link is with a diet high in fats and sugars and low in fruit and vegetables. Researchers have noted that in the past, IBD rates have been lower in non-Western countries such as Japan than in Western Europe and North America. However, over the past few decades, the number of people with IBD in Japan has been rapidly increasing. As many Japanese people now eat a more Westernised diet (a diet typically high in fats and sugars), the suggestion is that it could be this change in diet which has led to the increase in IBD.

There have been other research studies which have come to similar conclusions about diets high in sweets, cakes and/or red meat. Researchers have also found a possible link between UC and some types of fat, such as trans-unsaturated fats like linoleic acid (found in oils such as corn and sunflower oil). Lack of dietary fibre may also play a role. Another study found that women



whose diets contained a lot of fruit were less likely to develop Crohn's Disease, but not UC. Nevertheless, the overall picture is still not clear - some research findings contradict each other, and scientists continue to debate exactly whether and how food may play a part in causing IBD.

Can Food cure IBD?

Although diet may not cure IBD, some people may find that it helps to make small alterations to their diet. Some people have found that certain foods, for example spicy foods or dairy products, seem to trigger their symptoms or make them worse. On the other hand, some people may find they have no particular triggers - it varies from person to person. It may help to keep a

food diary in order to keep track of what you eat and when your symptoms occur. However, if you find that cutting out foods makes no difference, you should add them back into your diet, because you do not want to miss out on important nutrients. It is important to get advice from your doctor or from a qualified dietitian before you make any significant changes.

In some cases, particularly after surgery, or if you have a stricture (narrowing) in your small intestine, you may need to go on a special diet, or avoid certain foods.

For some people, particularly children and those with Crohn's Disease, it may be helpful to go on a liquid diet - this is called 'exclusive enteral nutrition'.

Public ignorance stigmatises children with IBD



The number of young people diagnosed with inflammatory bowel disease (IBD) in the UK has doubled over 20 years with average age at diagnosis now around 13. More young children than ever are diagnosed before the age of 10. A lack of awareness and understanding means the impact of IBD goes far beyond the physical, ruining childhood. Steroids are a common treatment and have distressing side effects which affect a child's appearance, mood and behaviour. Others suppress the immune system, leaving children more vulnerable to infectious diseases like chicken pox. Some children will also have a nutritional feed via a tube through their nose. Children with IBD will need to visit hospital for regular appointments and for invasive investigations, including endoscopy. Some children require surgery to remove diseased sections of the bowel and will need a stoma. Children with IBD can be small for their age, making them appear younger, which can make them a target for bullies. Combined with the strain of living with their condition, this can make them become withdrawn, anxious and depressed. Relapses can be particularly difficult to deal with emotionally. Young people with IBD are more likely to underachieve at school because recurring medical appointments necessitate days out of the classroom, fatigue reduces participation in activities and constant need to use toilets stops them taking trips. Even worse, some schools do not follow government guidance on medical conditions and penalise poor attendance. Symptoms can be exacerbated around stress-filled times such as exams.



Young people often feel embarrassed to talk about IBD so their day-to-day struggles with schoolwork, socialising and life get overlooked. This strains friendships at important times in their lives and they miss important aspects of childhood.

It can be easier to support a child with IBD in primary school than in secondary school, as children typically have one or two class teachers and teaching assistants who know them well and can liaise with parents about a child's health, treatment and specific needs.

Coping with secondary school for children with IBD is a challenge. Most children will have between 12 and 16 teachers and move around the school for different subjects. Urgent access to clean and private toilets is the most pressing concern for children, so it is important for all a child's teachers to be aware of their IBD and understand the impact this can have on their attitude and behaviour in school.

Children may arrive at secondary school with a diagnosis and their needs can be considered as part of the transfer from primary school, or they may become ill and get a diagnosis while at secondary school. Diagnosis of a life-changing and life-long condition has a significant emotional impact. Most people will go through a grief cycle of denial, anger and depression before reaching acceptance, and young people are no exception.

Cicra have developed excellent information sheets for both primary and secondary school's along with a "can't wait" card which children can use to show to staff.



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

Find us on Facebook: - York IBD Services

Email us: - yorkibdurses@york.nhs.uk