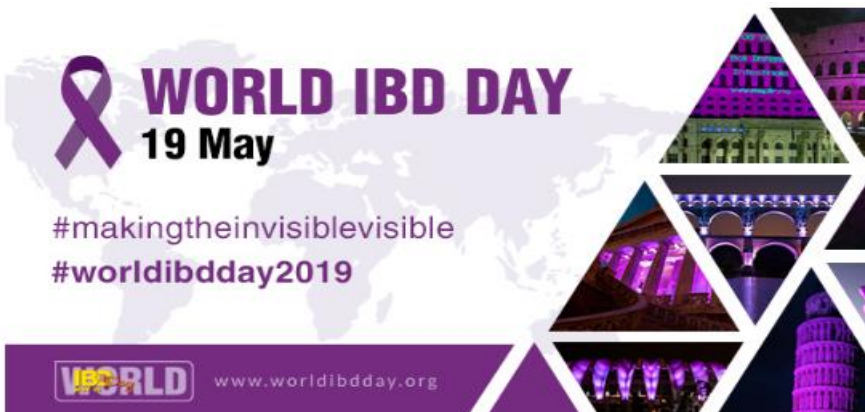


Spring/Summer 2019

# York IBD Matters



World IBD Day takes place on 19 May each year and unites people worldwide in their fight against Crohn's disease and ulcerative colitis. It is estimated that over 10 million people worldwide live with IBD and 300,000 of these people live in the UK with someone being diagnosed every 30 minutes. World IBD Day was created in 2010 by 5 founding members' countries and has gone from strength to strength and now reaches out to

over 50 countries and continues to grow. This year CCUK are encouraging people to "Speak Up" about suffering in silence with their disease and to raise awareness. There are wristbands to buy for £3.00 and also a Twibbon to add to your social media homepage –see <https://www.crohnsandcolitis.org.uk/>

In 2017 we published our experience of a pathway of care that helps us to monitor people who have Crohn's disease (see below). By using the marker of inflammation, faecal calprotectin, we found that we could accurately confirm the state of an individual's Crohn's disease activity. If the faecal calprotectin is low we can be confident that an individual is in remission of their disease and will stay in remission for some time to come. By contrast if the faecal calprotectin is high we know that the individual is likely to have active Crohn's disease even if they have no symptoms. This provides us an opportunity to intervene and optimise treatment.

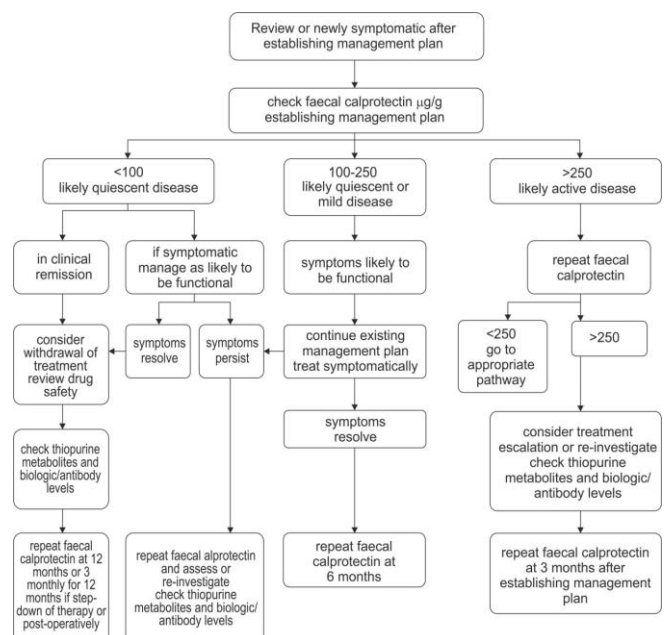
The pathway also allows us to set follow up times for patients based on whether the faecal calprotectin suggest the individual's Crohn's disease is active or under control.

Since faecal calprotectin has been such a useful tool for us in monitoring people with Crohn's disease we now want to conduct a research study to explore whether we should extend its role. We have been awarded some funds from the charity ForCrohns to conduct a pilot study. The purpose of the pilot study is to explore issues around individuals being in control of self-testing for faecal calprotectin.

Currently we are looking to recruit about 30 of our patients to take part in this study. In order to do

## A message from Dr James Turvill

you would need to have Crohn's disease and be established on treatment. If you would be interested in taking part in this study please contact York Teaching Hospital Research and Development Department either by email on: [Research@york.nhs.uk](mailto:Research@york.nhs.uk); or by phone: 01904 725459





# FINANCES

## What you need to know if you have IBD

For more on the eligibility criteria for using the benefits calculators, see: [gov.uk/benefits-calculators](https://www.gov.uk/benefits-calculators)

### WELFARE BENEFITS

**Personal Independence Payment (PIP)** is a welfare benefit for adults with a disability or long-term condition. PIP helps to cover the extra costs you may face if your Crohn's or Colitis makes it hard for you to get around or cope with daily living. There are criteria you need to meet to apply for PIP, including how long you have lived in the UK. For more information, see: [gov.uk/pip](https://www.gov.uk/pip)  
If you get Disability Living Allowance (DLA), PIP is replacing this. You don't need to do anything if you are currently receiving DLA, unless your circumstances change. The Department of Work and Pensions (DWP) will invite you to apply for PIP. When they invite you, you must apply within 28 days or your DLA payments will stop.

**Attendance Allowance.** If you've reached State Pension age and you do not receive DLA or PIP, you can apply for Attendance Allowance instead. This benefit helps with extra costs if your condition is severe enough that you need someone to look after you. But you don't have to have someone caring for you in order to claim. For more information about attendance allowance, see: [gov.uk/attendance-allowance](https://www.gov.uk/attendance-allowance)

**Universal Credit** is a once-a-month payment to help with your living costs (except if you live in Scotland, where it may be twice a month). Universal Credit is a benefit that's recently replaced various existing benefits, including:

- Child Tax Credit
- Housing Benefit
- Income Support
- Income-based Jobseeker's Allowance (JSA)
- Working Tax Credit
- Income-related Employment and Support Allowance

see: [gov.uk/universal-credit](https://www.gov.uk/universal-credit)

For more information about Finances and benefits see the new CCUK leaflet on Finances

*Living with Crohn's or Colitis can be expensive. You might worry about being too sick to work or facing extra costs like prescriptions and increased household bills. It can be overwhelming, but there are lots of potential sources of support for you.*

### STATUTORY SICK PAY

You can get Statutory Sick Pay (SSP) if you're too ill to work. It's paid by your employer for up to 28 weeks. You will need to meet certain criteria to receive SSP. See the Government website for further information: [gov.uk/statutory-sick-pay](https://www.gov.uk/statutory-sick-pay). If you are self-employed, you will not be able to claim SSP. But you may be able to claim other benefits, including Universal Credit, Council Tax Reduction, Personal Independence Payment and Employment and Support Allowance.

### DISABILITY AND SICKNESS BENEFITS

If you've had to leave employment, or work reduced hours because of sickness, there are a number of benefits you can claim. You may also be able to claim these benefits if you're working full-time but you're on a low income and you're sick.

**Benefits calculators** It can be complicated to find out what benefits you may be eligible for. As a first step, you might find it useful to enter your details into a benefits calculator. These are free to use and anonymous, and they can help you to find out:

- what benefits you could get
- how to claim
- how your benefits will be affected if you start work.

Before you start, it is a good idea to make sure you have all the information you will need. You can find out more about this on the Turn2us website: [turn2us.org.uk/get-support](https://www.turn2us.org.uk/get-support)

The Government website [gov.uk](https://www.gov.uk) recommend the following benefits calculators:

- Turn2us: [benefit-calculator.turn2us.org.uk/AboutYou](https://www.benefit-calculator.turn2us.org.uk/AboutYou)
- Policy in Practice: [betteroffcalculator.co.uk/#/free](https://www.betteroffcalculator.co.uk/#/free)
- entitledto: [entitledto.co.uk](https://www.entitledto.co.uk)

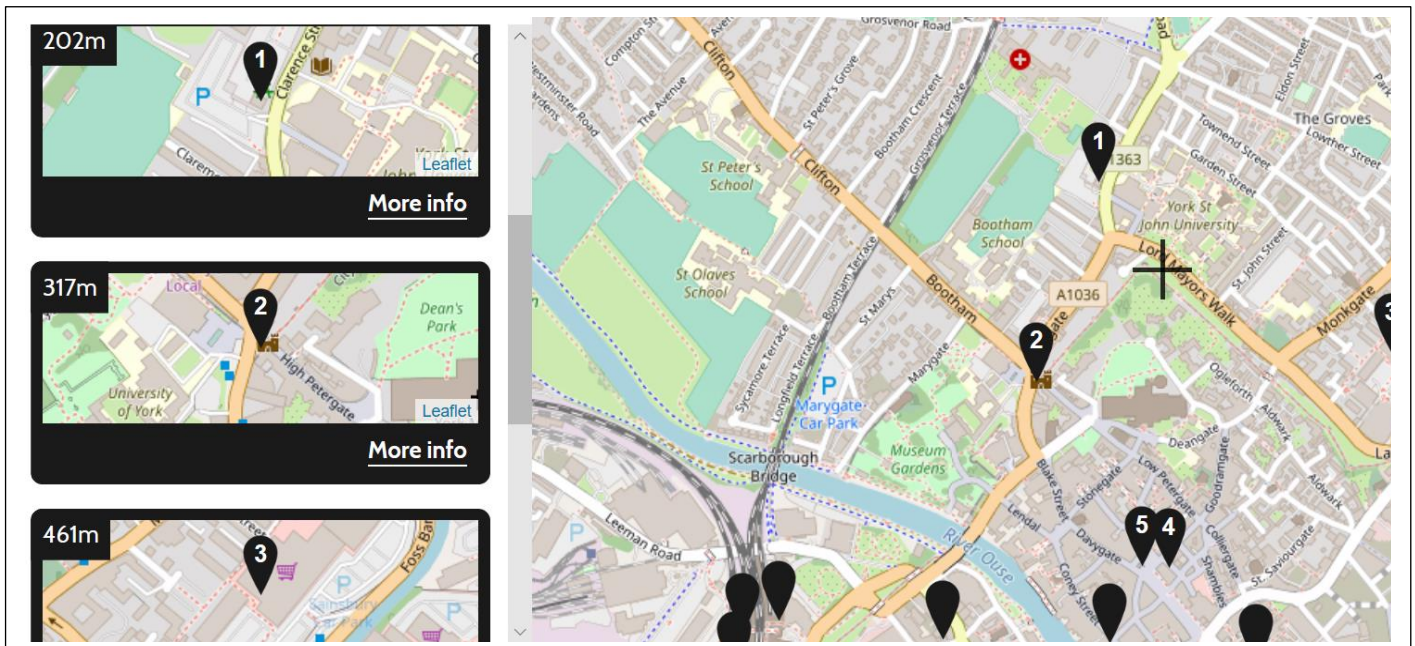
The benefits calculators will provide accurate results if you are a British citizen.



# The Great British Public Toilet Map

The Great British Public Toilet Map is a website where you can search for public toilets in your area. It is the UK's largest database of publicly accessible toilets, with over 11000 facilities. This includes toilets in shops and cafes where they let non-customers use their loo, such as those in Community Toilet Schemes. You can help by adding toilets that you know about to their website.

**Use our Loos!!** is the first national community toilet scheme, created by the British Toilet Association, Domestos and the **Great British Public Toilet Map**, with the ambition to unlock the loos that are hidden in high street cafes, restaurants, coffee shops and bars and open them up to the community. As more public loos are closed, they are asking that more loos are made public.



The 5 nearest toilets are listed, you can click "more info" to find out about each toilet's features and then "get direction" which links to Google Maps. <https://www.toiletmap.org.uk> for more information



The Great British Public Toilet Map

proudly sponsored by 

## Have you got your Can't Wait Card and RADAR Key?

Joining Crohn's Colitis UK (CCUK) for just £19 a year or £1.25 a month direct debit provides you with a "Can't Wait" card and RADAR key.

The Can't Wait Card has been designed to be discreetly tucked away in a purse or wallet, the card is available in 30 different languages for travelling abroad. The Can't Wait Card makes it easier for people with IBD to ask to use toilets in shops, restaurants and other buildings (which may not be public facing), without having to give a long explanation about their condition.

A RADAR Key is a large universal key used to open RADAR locks. These locks are commonly installed in publicly accessible toilets, and often used in restaurants and other venues. In fact, there are over 9,000 accessible toilets with RADAR locks across the UK. Having a RADAR key means you do not need to wait for a member of staff to unlock the toilet for you, you can just let yourself in.



# UK's first predictive test for Crohn's and Colitis

**PREDICTSURE IBD™**, is a new simple test that could enable personalised treatment of Crohn's and Colitis. Scientists at the University of Cambridge have developed a new test that can reliably predict the future course of Crohn's Disease or Ulcerative Colitis, transforming treatments for people with the conditions and paving the way for a personalised approach. In the latest study, published in the journal *Gut*, researchers at the Department of Medicine, University of Cambridge, worked with 69 people with Crohn's to see whether it was possible to develop a useful, scalable test by looking at whole blood samples alongside CD8 T-cells and using widely-available technology.

The team used a combination of machine learning and a whole blood assay known as qPCR a relatively simple tool used in NHS labs across the country to identify genetic signatures that were the same as the two groups (mild and severe) from their previous study.

The researchers then validated their findings in 123 people with Crohn's or Colitis recruited from clinics in Cambridge, Nottingham, Exeter and London. Dr James Lee

Clinical Research Fellow, at Cambridge University explains

*"This is important as it could enable doctors to personalise the treatment that they give to each patient. If an individual is likely to have only mild disease, they don't want to be taking strong drugs with unpleasant side-effects. But similarly, if someone is likely to have a more aggressive form of the disease, then the evidence suggests that*



*the sooner we can start them on the best available treatments, the better we can manage their condition."*

The accuracy of the test is comparable to similar biomarkers used in cancer, which have helped transform treatment. They found the new test was 90-100% accurate in correctly identifying people who did not require multiple treatments.

The test is now being developed further by PredictImmune and has led to the creation of PredictSURE IBD™. It is a simple blood test which can provide valuable information to doctors about the expected way people's condition will affect their bodies. The team is also involved in a £4.2 million trial to see whether using the biomarker to guide treatment at the time of diagnosis can lead to better outcomes for people with Crohn's or Colitis.

Helen Terry, Director of research, Crohn's Colitis UK explained



*"We're now at the stage where this simple blood test will be available in the NHS. This could drastically change the lives of people with Crohn's or Colitis as it means they can be started on the best medication for them sooner. I am also pleased to see how our investment into research can lead to tangible benefits for patients, taking it from the lab into real IBD clinics."*

The PredictSURE IBD™ test has 10 years of research behind it, with Crohn's & Colitis UK providing early support and

**Visit our website:** - [www.yorkhospitals.nhs.uk/our-services/a-z-of-services/inflammatory-bowel-disease/](http://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](mailto:yorkibdurses@york.nhs.uk)  
[scarboroughibdurse@york.nhs.uk](mailto:scarboroughibdurse@york.nhs.uk)