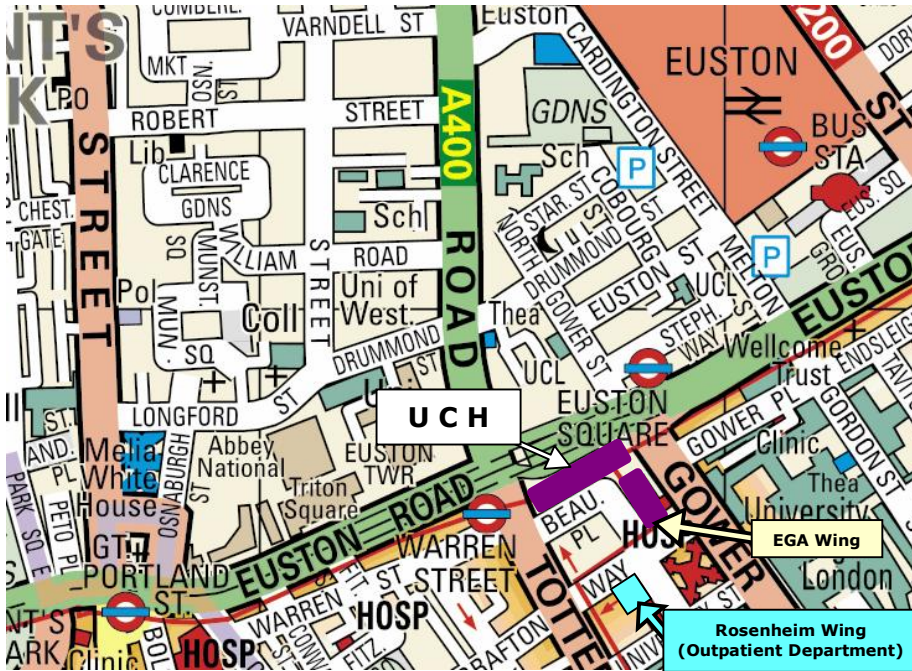


## HOSPITAL LOCATION



© with permission from Bartholomew Limited (2006)

### Getting to University College Hospital

#### **By bus:**

Coming from the south – Bus numbers: 10, 73, 24, 29, 134 (get off at Warren Street Station stop)

Coming from the north – Bus numbers: 10, 24, 29, 73, 134 (get off at 1<sup>st</sup> stop in Gower Street)

Coming from east or west – Bus numbers: 18, 27, 30, 88 (get off in Euston Road)

#### **By tube:**

Inbetween Warren Street (Northern/Victoria Lines) and Euston Square (Circle/Hammersmith & City/Metropolitan Lines) Underground Stations



## UNIVERSITY COLLEGE HOSPITAL INFLAMMATORY BOWEL DISEASE SERVICE

## INDEX

Telephone numbers	1
About the Inflammatory Bowel Disease Service	2
Consultants	2
Inflammatory Bowel Disease Clinical Nurse Specialists	2
Specialist Dietician	2
Outpatient Clinic	2
What to expect when you attend the Clinic	2
Making the Clinic work for you	3
Correspondence	3
Multidisciplinary Team (MDT) Meetings	4
Surgery	4
Pharmacy and Medications	4
What to do if you become unwell	4
Tests	5
Research and Clinical Trials	7
Sources of Useful Information	8
About University College Hospital	9
About the Department of Gastroenterology	9
Who's who?	9
Diagram of the Digestive System	10
Hospital Location / Getting to University College Hospital	11

### TELEPHONE NUMBERS

**Hospital switchboard:** 0845 155 5000

**Dr Bloom / Dr McCartney's Secretary:** 020 7380 9126

**Dr Langmead's Secretary:** 020 7380 9311

**Lucy Medcalf / Hannah Middleton, IBD Nurse Specialists:**  
020 7380 6803 (voicemail) or 07908 468 399 (mobile)

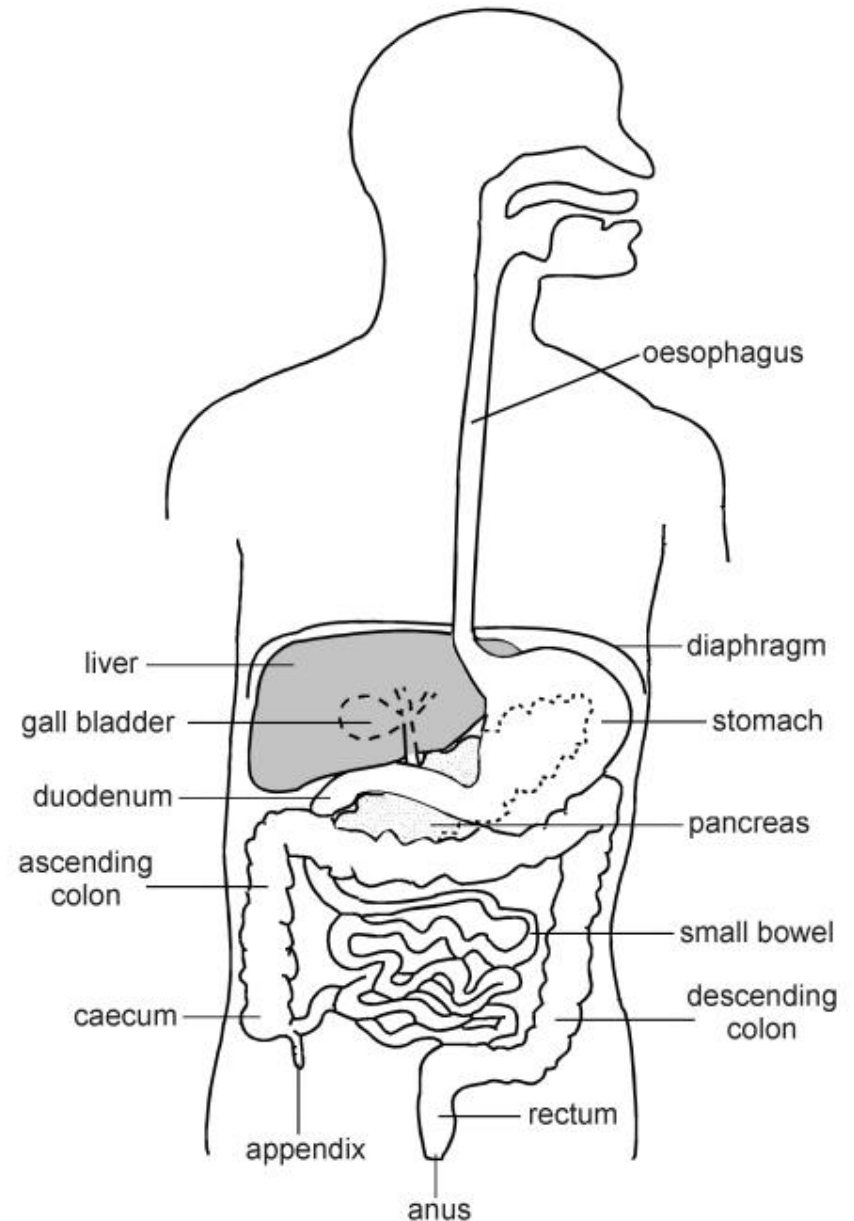
**Belinda Theis, Trials Coordinator:** 020 7380 9240 (voicemail)

**Outpatient Appointments:** 020 7380 9393

**Endoscopy Appointments:** 0845 155 5000, extension 3931

**X-ray Appointments:** 020 7380 9010

## DIAGRAM OF THE DIGESTIVE SYSTEM



## ABOUT UNIVERSITY COLLEGE HOSPITAL

The new University College Hospital was opened in June 2005 and replaced the facilities previously located at the Middlesex Hospital.

## ABOUT THE DEPARTMENT OF GASTROENTEROLOGY

Most of the work of the Department of Gastroenterology is based on the second floor of the Hospital, in the 'Podium' where we have a large fully equipped Endoscopy Unit. This is where tests to look inside the stomach or bowel are performed ('endoscopies') along with tests to measure how well the gut functions. As well as looking after patients with inflammatory bowel disease, the department sees patients with benign and malignant disorders of the oesophagus ('gullet'), stomach, small intestine and large intestine (colon), the liver and biliary tract, and the pancreas.

## WHO'S WHO?

**Consultant Physician:** Qualified doctor who has completed training and is fully responsible for patients under his/her care. He/she heads a team of doctors in training to diagnose, treat and manage patients.

**Clinical Nurse Specialist:** a qualified Nurse who has specialised in the treatment and management of a particular type or group of conditions.

**Dietician:** Person qualified in nutrition who can advise on healthy diets or specialised diets as necessary.

**Gastroenterologist:** Consultant Physician who specialises in diseases and conditions of the gastrointestinal tract (digestive system / the gut).

**Histopathologist:** Qualified doctor who specialises in the examination of tissues and cells.

**Medical student:** A student studying medicine (not qualified as a doctor)

**Pharmacist:** A person trained to prepare and give out medicines and to give information about them.

**Radiologist:** Qualified doctor who specialises in scanning techniques to 'image' (show pictures) of the body to help diagnose and monitor conditions.

**Senior Specialist Registrar / Research Fellow / Clinical Fellow / Senior House Officer / House officer:** Qualified doctors still in training.

**Surgeon:** A qualified doctor who specialises in surgery (operations) to treat conditions. Can either be in training still, or have completed training (consultant surgeon).

## ABOUT THE INFLAMMATORY BOWEL DISEASE (IBD) SERVICE

We have three consultants who specialise in inflammatory bowel disease:

- Dr Stuart Bloom
- Dr Sara McCartney
- Dr Louise Langmead

A team of junior doctors – Senior Registrars, Research Fellows, Senior House Officers and House Officers work under the supervision of the consultants.

We also have two Inflammatory Bowel Disease Clinical Nurse Specialists and a specialist dietician (see below).

### Inflammatory Bowel Disease Clinical Nurse Specialists

Lucy Medcalf and Hannah Middleton are able to offer advice in person (by appointment), by telephone, email or letter. They can provide you with information leaflets and further information on the inflammatory bowel diseases, drugs and other treatments you may be prescribed.

Lucy and Hannah also have their own clinic to give drugs and monitor patients on certain treatments.

Telephone: 020 7380 6803 (voicemail) / 07908 468 399 (mobile)

email: lucy.medcalf@uclh.nhs.uk / hanna.middleton@uclh.nhs.uk

Address: Department of Gastroenterology (2<sup>nd</sup> Floor Maple House), Ground Floor, Rosenheim Building, 25 Grafton Way, London. WC1E 6DB

### Specialist Dietician

Derbhla O'Sullivan has expertise in inflammatory bowel disease. You can ask to see Derbhla for advice when you attend the Clinic: if possible she will see you then, otherwise you can make an appointment to come back and see her.

Telephone: 020 7380 9289

## OUTPATIENT CLINIC

The adult 'IBD Clinic' is held on Wednesday mornings, between 08.30–12.30 hr, on the 5<sup>th</sup> Floor of the Rosenheim Building in Grafton Way. Dr McCartney holds a clinic for adolescents every week on Tuesdays between 14.00–17.00 hr (Lower Ground Floor of the Elizabeth Garrett Anderson Wing).

### What to expect when you attend the Clinic

After you arrive in Clinic and have reported to the Receptionist, you will be weighed by the nurse or Health Care Assistant and then be asked to take a seat until you are called to see the doctor. New patients will have their height measured, and may be asked to provide a urine sample.

A large number of patients attend the Clinic. Usually two or all three consultants, three of their senior registrars, the Clinical Nurse Specialists and dietician will be present. It is likely you will have been allocated to a consultant's list, but you may be seen by any one of the doctors as all patients are jointly cared for. At the end of the Clinic a meeting is held so that any decisions taken on patients can be discussed.

If you are a new patient, the doctor will discuss your symptoms and medical history with you in detail, and examine you. You will be advised to have one or more of a variety of tests (see 'Tests', page 6) so that the nature and full extent of your condition can be determined.

'Follow-up' patients may also require tests – either as part of a scheduled programme of monitoring of their condition – or if the condition relapses or new symptoms arise.

Once you have seen the doctor, you will be asked to make a further appointment with the Receptionist.

It is important that you are involved at all stages in decisions made about your condition. We like patients to ask questions and we welcome patients telling us if they need extra information or time to help in this process.

### **Making the Clinic work for you**

Currently, except for blood tests which are performed straight away, the only test you can book and arrange an appointment for immediately is an ultrasound scan. All other appointments for tests will be sent to you in the post. It is hoped that in the not too distant future all tests will be bookable when you take the form to the relevant department after your appointment.

If you need to book any tests it is worth checking that the follow-up appointment is scheduled for after the test and that this allows enough time for the doctor to receive the result before you see him/her again. If necessary, please contact the outpatient to rebook the appointment (see 'Contact telephone numbers' on page 1).

Some patients need to come back to the Clinic more often than others, but it is important to attend your appointments as requested by the doctors as it is necessary to keep your condition under review. Even if you feel perfectly well you may need to have your blood checked because of the treatment you are being given, or have your bone density measured (see 'DEXA scan' in 'Tests', page 6) for example.

### **CORRESPONDENCE**

You will routinely receive a copy of any letters sent to your GP about you. If there is something in the letter you do not understand please either ask your GP or contact the clinical nurse specialists who will be happy to help.

## **SOURCES OF USEFUL INFORMATION**

### **National Association for Colitis and Crohn's Disease (NACC)**

Address: 4 Beaumont House, Sutton Road, St Albans, Herts. AL1 5HH  
Information Line: 0845 130 2233 (or 01727 844296)

Email: [nacc@nacc.org.uk](mailto:nacc@nacc.org.uk)

Website: <http://www.nacc.org.uk/content/home.asp>

NACC brings together people of all ages who have Ulcerative Colitis or Crohn's Disease, their families and the health professionals involved in their care. The organisation provides:

- support through 70 groups, the NACC-in-Contact Support Line and individual welfare grants
- An Information Service by telephone and email
- a range of Information Sheets on specific topics, including benefits

### **CORE (formerly known as Digestive Disorders Foundation)**

Address: 3 St Andrew's Place, Regents Park, London, NW1 4LB

E-mail: [info@corecharity.org.uk](mailto:info@corecharity.org.uk)

Website: [www.corecharity.org.uk](http://www.corecharity.org.uk)

CORE issue booklets and leaflets to help you understand the whole digestive system e.g. diverticulitis, gall stones etc.

### **Crohn's in Childhood Research Association (CICRA)**

Address: Parkgate House, 356 West Barnes Lane, Surrey, KT3 6NB

Telephone: 020 8949 6209

Email: [support@cicra.org](mailto:support@cicra.org)

Website: [www.cicra.org](http://www.cicra.org)

### **ia (The Ileostomy and Internal Pouch Support Group)**

Address: Peverill House, 1-5 Mill Road, Ballyclare, Co Antrim, BT39 9DR

Telephone: 0800 018 4724 or 028 9334 4043

E-mail: [info@the-ia.org.uk](mailto:info@the-ia.org.uk)

Website: [www.the-ia.org.uk](http://www.the-ia.org.uk)

**Young ia:** [www.youngia.org.uk](http://www.youngia.org.uk)

The ia give advice to anyone who has an 'ostomy'. They are also happy to visit people in their own homes to offer counselling

### **Irritable Bowel Syndrome Network**

Address: IBS Network, Unit 5, 53 Mowbray Street, Sheffield, S3 8EN

Telephone Helpline: 0114 272 3253

E-mail: [info@ibsnetwork.org.uk](mailto:info@ibsnetwork.org.uk)

Website: [www.ibsnetwork.org.uk](http://www.ibsnetwork.org.uk)

The IBS Network is an independent, self help organisation run by people with IBS. The helpline is staffed by qualified nurses who specialise in IBS

## RESEARCH AND CLINICAL TRIALS

We have an active programme of research, ranging from looking at the different behaviours of certain cells in the blood to trials of new drug treatments to try to help us better understand these diseases and improve treatments for them. All research we undertake has been approved by an authorised 'Research Ethics Committee' and the Joint University College London Hospitals / University College London Research and Development Department, which means the research has been assessed by appropriately trained and qualified people who have been satisfied the proposed research is 'ethical', that is to say it is being undertaken to address a valid question, the methods used in the course of the research are in keeping with acceptable standards and that those who will be doing the research are properly trained and qualified to do so.

It is important that you know you are under no obligation to participate in any of our research studies: if you are approached about a study and say 'no' this will not affect your normal care in any way. If you decided to take part in a research study or trial and changed your mind you can drop out at any time – even if you have started – and you do not need to give a reason: again this would not affect your normal care in any way.

Any information about you used for research is carefully protected and covered by the Data Protection Act. If you are asked to consider any research studies or trials you will be given a detailed 'Patient Information Sheet' which will tell you in detail about the why the research is being done, why you have been asked if you wish to participate, what doing so would involve, what information is collected and what happens to this.

We wish to ensure that all our patients have the opportunity to take part in trials of new drugs when possible. Usually a patient is considered for a trial when their condition 'flares' (becomes less well controlled) though some trials are designed for patients who have been well for a good length of time (usually drugs designed to help patients stay in remission). If between Outpatient appointments you develop a worsening of your symptoms, before making any changes to your regular medications, we would ask you to contact Lucy Medcalf or Hannah Middleton – the IBD Nurse Specialists, so they can advise you if there any new treatments available that you may be interested in before doing so. The reason for asking you not to change the dose or type of your medications is that to try out most new drug treatments patients need to have been on 'stable' doses of regular medications for at least four weeks.

If you wish to know what research studies are currently being conducted you can contact the Clinical Trials Coordinator, Belinda Theis:

Telephone: 020 7380 9240 (voicemail)

Email: [belinda.theis@uclh.nhs.uk](mailto:belinda.theis@uclh.nhs.uk)

## MULTIDISCIPLINARY TEAM (MDT) MEETINGS

We hold a Multidisciplinary Team (MDT) Meeting every Friday morning. During this meeting we are able to discuss any patient who has had a new test or whose condition has changed with specialist surgeons, radiologists and histopathologists to help ensure the best course of action is advised. Such meetings have been shown to be of benefit to patients.

## SURGERY

We work closely with our surgical colleagues as some patients with inflammatory bowel disease will need an operation during the course of time. The four consultant surgeons are: Professor Paul Boulos, Mr Austin O'Bichere, Mr Alastair Windsor and Mr Richard Cohen.

## PHARMACY AND MEDICATIONS

The hospital policy is for a one month supply of medications to be given to patients. After this, except in the case of a few less common drugs, you will need to get a repeat prescription from your GP. As it is likely you will have a number of prescriptions throughout the course of a year, for those of you on more than one drug who pay for your prescriptions, it is worth thinking about buying a prepayment certificate (PPC) to reduce the cost.

## WHAT TO DO IF YOU BECOME UNWELL

Relapses (worsening) of your inflammatory bowel disease can be uncomfortable and distressing. If you do become unwell we can see you quickly in the Clinic to find out what is happening and start effective treatment. **We suggest that in the first instance, if you think you are experiencing a relapse, you contact Lucy Medcalf of Hannah Middleton, our Clinical Nurse Specialists**, either by telephone or email, and discuss your condition with them. You may wish to contact your GP, and of course if you are feeling very unwell 'out of hours' this is entirely appropriate, however during weekdays, and if you feel you are experiencing 'early' signs of relapse, it is worth contacting Lucy or Hannah direct as they will be able to offer specific advice and arrange for you to be seen in the next Clinic if needs be.

Because of the possible availability of new drugs in the clinical trials we have running (see 'Research and Clinical Trials' on page 7), another good reason for you to call Lucy or Hannah is to make sure you are offered one of these new treatments if your condition is suitable. It is important therefore that you do not alter the dose of your medications (for example increase the number of Pentasa or Asacol tablets you are taking) or start something new (like Asacol suppositories or Predfoam enemas) until you have spoken with Lucy or Hannah, as this would prevent you from being able to try a new trial treatment.

## TESTS

**Abdominal X-ray:** X-ray of the abdomen (stomach area) which can show any distension (enlargement) of the bowel, abnormal gas patterns and constipation.

**Barium follow-through:** Barium, a liquid which shows up on X-rays (known as 'contrast') is swallowed and then the doctor performing the test will 'follow' the contrast using 'fluoroscopy' (X-rays) as it travels through the small intestine and try and use the barium to coat the wall of the intestine to show up any abnormalities such as ulcers and narrowing.

**Biopsy:** removal of a sample of tissue for examination under a microscope. This may be done at the time of an endoscopy (colonoscopy / sigmoidoscopy / gastroscopy). The type and amount of inflammation in the cells is helpful in diagnosis and monitoring of your condition.

**Blood tests:** A sample of blood is taken from a vein in your arm using a fine needle. The blood is collected into different types of tubes and sent to the laboratory for analysis. It can be a little uncomfortable but is rarely painful. Your condition can cause alterations in the levels of certain cells, proteins, salts, hormones and other properties of your blood, and we use these results to help assess how 'active' (bad) your disease is and how well you are responding to treatment. The 'Phlebotomy' (blood taking) department is just inside the entrance to the Clinics (first right as you come through the door).

**Chest X-ray:** X-ray of the chest to show any abnormalities in the lungs or pleural cavity (membranous covered area around the lungs).

**Colonoscopy:** a test using a long thin bendy camera to look inside the colon (large bowel). You will need to take some medicines to cleanse your bowel beforehand. The camera is inserted through the anus (back passage). You will be given a sedative and pain killer into your vein to reduce any discomfort you may experience. A full information leaflet describing the procedure is available from the Endoscopy Unit.

**CT (computed tomography) scan:** A CT scanner takes lots of X-ray pictures of your body from different angles and then feeds the pictures into a computer which creates an image of what is inside for the doctors to look at. You will be given a special dye into a vein which makes the blood vessels very bright in the pictures and also adds 'contrast' (varying degrees of brightness) to the organs depending on the blood flow in them, which helps make interpretation of the pictures clearer. The X-rays are painless, but the injection of dye can sometimes be a little uncomfortable.

**DEXA scan:** DEXA stands for 'dual energy x-ray absorptiometry'. It is a test that measures the density of bones. Patients with inflammatory bowel disease can develop thinning of their bones either because of problems absorbing vitamins or as a side effect of treatment. The scan is painless and involves lying still on an X-ray table for 10-15 minutes whilst low energy X-rays are directed at the bones. The healthier (denser) the bones, the harder it is for X-rays to get through.

**Endoscopy:** a test using a long thin bendy camera to look inside the gut. The stomach, duodenum (small intestine) and colon can be examined in this way.

**Gastroscopy:** a test using a long thin bendy camera to look inside the stomach. The camera is passed through your mouth and down your throat into the stomach. A local anaesthetic will be sprayed into your throat so that you are able to swallow the tube. If you wish you can be given a sedative into your vein to reduce any discomfort you may experience. A full information leaflet describing the procedure is available from the Endoscopy Unit.

**MRI (magnetic resonance imaging) scan:** This type of scan builds up a picture of the inside of the body using magnetism instead of X-rays. You may be asked to drink a liquid to act as a contrast inside your intestines. Sometimes dye is injected into a vein to help produce a different contrast (varying degrees of brightness) of the tissues. The scan is painless (but is very noisy).

**SeHCAT scan:** This scan looks to see if your intestine absorbs bile (a salt made by the liver) properly. It involves swallowing a capsule containing a synthetic bile salt linked to a radioactive tracer (a very small safe amount) and having an X-ray after 3 hours and again one week later.

**Sigmoidoscopy:** a test to look inside the left side, lower half of the colon, of which the 'sigmoid colon' is a part. There are two types of sigmoidoscopy: 'rigid' and 'flexible'. A rigid sigmoidoscopy uses a disposable 'rigid' plastic tube through which the doctor can see the lower end of the colon. This can be done in the Outpatient Clinic; a flexible sigmoidoscopy uses a long thin bendy camera, which can reach further. Like the colonoscopy, the tube or camera is inserted through the anus (back passage). For the flexible sigmoidoscopy you will be given a sedative and pain killer into your vein to reduce any discomfort you may experience. A full information leaflet describing the 'flexible' procedure is available from the Endoscopy Unit.

**Stool sample:** A sample of your stool (faeces) is sent to the laboratory to make sure you do not have an infection. The nurse in the Clinic will give you everything you need to collect the sample.

**Ultrasound scan:** Sound waves are used to build up a picture of the inside of the body. A 'probe' (large microphone) is rubbed across the abdomen: sound waves are sent out and bounce back, and these are fed into a computer which creates the picture. The test is painless.