

This leaflet has been written to help you complete the 'Simple Clinical Colitis Index' we use when you are on biological treatment. This helps us to score your ulcerative colitis activity.

What is the Simple Clinical Colitis Index?

This is a simple questionnaire used to assess how severe your ulcerative colitis symptoms are. The score is worked out by asking you questions about:

- how often you open your bowels
- whether you have to go to the toilet with urgency
- if there is any blood in your stools
- your general wellbeing and symptoms outside your guts, which can sometimes be related.

All the answers need to reflect your gastrointestinal health status within the last 24 to 48 hours.

Notes to help with each question

Bowel frequency (day)

Circle on the horizontal row the numbers applicable to you (how many times you open your bowel from morning until you go to bed).

Bowel frequency (night)

How many times you open your bowels during the night.

Urgency

Do you have a sudden, intense sensation of needing to go to the toilet or having to rush to get there?

You will be asked to circle the word which describes it the best:

- **Hurry** – you need to go to the toilet quickly.
- **Immediate** – you need to go to the toilet at once, without delay.
- **Incontinence** – any accidental or involuntary loss of stool (inability to control your bowel movements).

Blood in your stool

If there is any visible blood in your stool, you will need to circle the word which describes it best:

- **Trace of blood** – a very slight amount of blood.
- **Occasionally frank** – obvious blood in your stool; not every time, but now and then.
- **Usually frank** – obvious blood in the stool on most occasions.

General wellbeing

Circle on the horizontal row the word which best describes your general wellbeing.

Extra-intestinal manifestations

More than one-third of people with IBD are affected by symptoms outside their guts. These are called 'extra-intestinal manifestations' or EIMs. A detailed explanation of these is shown in the next section.

EIMs may impact your quality of life significantly. They most frequently affect the joints, skin or eyes, but can also involve other organs, such as the liver, lungs, or pancreas. You may need specific treatment, depending on which areas are affected.

EIMs can occur when inflammatory bowel disease is in remission and during or after a flare-up.

Please see the following details for further information. If you are still unsure how to complete the form, please ask one of the IBD nurses.

Examples of EIMs

Arthralgia

This means joint pain (not muscular pain).

Erythema nodosum

This is a condition that causes red, rounded lumps (nodules) to form below the skin surface, most commonly on the shins.

Aphthous ulcers

These are ulcers in the mouth.

Uveitis

This is inflammation (swelling) of the middle layer of the eye, called the uvea or uveal tract. It can cause your eyes to become red and painful.

Fissure

This is a small tear in the skin around the opening of your anus. It can cause severe pain and sometimes bleeding, usually after a

bowel movement. Anal fissures are usually found at the part of your anus close to your back, in the line with the cleft of your buttocks.

Abscess

This is a painful collection of pus, usually caused by a bacterial infection. It can develop anywhere in the body. Skin abscess develop under the skin, whereas an internal abscess can develop inside the body, in an organ or in the spaces between organs. Symptoms are usually pain in the affected area, a high temperature and generally feeling unwell.

Pyoderma gangrenosum

This is a rare and serious skin rash, in which a painful nodule or pustule breaks down to form an ulcer, which gradually gets bigger and bigger.

Pyoderma gangrenosum can cause deep red ulcers with sharply defined borders and are extremely painful.

Fistula

This is an abnormal channel or passageway which connects one internal organ to another, or to the outside surface of the body. Many fistulas (or fistulae) involve the bowel or intestine. A fistula might connect two parts of the bowel to each other, or the bowel to the vagina, bladder, or skin.

When you have finished the score

Many thanks for completing this form. Please do return it to the nurse overseeing your infusion or blood test at this time. If you are completing it at home, please return it to the IBD nursing team via gastroOPD@nhs.net.

We will then make sure it is recorded in your hospital notes and can contribute to the overall assessment of your progress.

How to contact us

Tel: **01865 228 772**

Email: **ibd.advice@nhs.net**

We would like to include photos of extra-intestinal manifestations (EIMs) in this leaflet. If you experience any EIMs and you would be willing to have anonymous photos taken of them, please do let us know.

If you have a specific requirement, need an interpreter,
a document in Easy Read, another language, large print,
Braille or audio version, please call **01865 221 473**
or email **PALS@ouh.nhs.uk**

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