

Condition Insight Report (CIR)

Ulcerative Colitis

Version 1.0

**Created in collaboration with
Crohns & Colitis UK**

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Slide 2 – Overview

Slide 3 – Fluctuations and reliability

Slide 4 – Sensitivities and lives experience

Slide 5 – Functional impact 1-3

Slide 6 – Functional impact 4 & 6

Slide 7 –Functional impact 5

Slide 8 – Functional impact 12

Slide 9-Function impact 7-9

Slide 10-Functional impact 10 & 11

Slide 11 – Additional reading/ resources

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Overview

Brief overview of the condition.

Ulcerative colitis is a life-long condition where the colon and rectum become inflamed.

The colon is the large intestine (bowel) and the rectum is the end of the bowel where poo is stored.

Small ulcers can develop on the colon's lining, and can bleed and produce pus.

What causes ulcerative colitis?

Ulcerative colitis is thought to be an immune-mediated condition.

This means the immune system, the body's defence against infection, goes wrong and attacks healthy tissue.

The most popular theory is that the immune system mistakes harmless bacteria inside the colon as a threat and attacks the tissues of the colon, causing it to become inflamed.

Exactly what causes the immune system to behave in this way is unclear.

Many experts think it's a combination of genetic and environmental factors.

Did you know...?

- ❖ 75% of people have recurrent episodes of varying severity lasting over many years.
- ❖ 10-15% experience an aggressive form of the disease. People with extensive disease may develop potentially life threatening complications such as perforation of the bowel or sepsis.
- ❖ 10 in 100 will need major surgery within 10 years of diagnosis This depends on where and how much of the colon is affected.
- ❖ Some people experience only mild and infrequent symptoms which have minimal impact on life.
- ❖ BSG guidelines state that up to 90% have one or more relapses
- ❖ BSG guidelines state that 15-25% will require hospitalisation for an acute severe flare of disease at some stage in the natural history of their disease

Presenting Symptoms

Ulcerative Colitis

Inflammation and ulcers develop on the inner lining of the large bowel (colon and rectum) that may bleed and produce mucus or pus.

- Symptoms include abdominal pain, diarrhoea, urgency, blood in stools and feeling generally unwell or feverish.
- Loss of appetite and weight loss are common.
- Anaemia can result from blood loss and/or reduced intake or absorption of nutrients.
- Fatigue (extreme tiredness that does not go away with rest) is common, and often a result of frequently waking up at night to open bowels, blood loss and malnutrition.

Up to half of all people with Ulcerative Colitis experience symptoms outside the gut.

- Joint problems including pain and arthritis affect around a third of people.
- Skin problems can occur including mouth ulcers, blisters and ulcers on the skin, and painful red swellings (erythema nodosum, pyoderma gangrenosum), usually on the legs.
- Osteopenia and osteoporosis are complications of Ulcerative Colitis as a result of inflammation, drug side effects or malabsorption of nutrients.
- Eye problems can include uveitis, episcleritis or scleritis and lead to loss of vision if untreated.
- Depression is experienced by 1 in 4 people, living with a long-term condition, pain, fatigue and social isolation all contribute.
- People are twice as likely to develop blood clots (including deep vein thrombosis) than the general population.
- There is also an increased risk of developing colorectal cancer.

Fluctuations & Treatment



Ulcerative colitis is a fluctuating condition with episodes of inflammation (flare-ups) and remission (when symptoms improve or go away). Severe episodes of abdominal pain and diarrhoea may need hospitalisation. Some people need surgery which can result in a stoma. People with severe disease are unwell and may have low body weight.

Diagnosis

- Diagnosis is based on medical history, clinical picture, blood and stool tests and abdominal investigations.
- MRI and CT scans, colonoscopy and ultrasound scans are commonly used to diagnose the condition and distinguish it from other conditions of the gut.

Treatment

Drug treatment aims to reduce inflammation, improve symptoms, control flare-ups and maintain remission.

Surgery may be needed when there is:

- Poor response to long-term medical treatment
- Fistula or stricture
- Emergency problems including severe diarrhoea with bleeding, dehydration and fever
- Rare complications such perforation of the bowel
- Cancer of the colon or rectum.
- Poor growth or development in children; When a patient chooses surgery in preference to medicines (which may have side effects that are difficult to cope with)

Reliability

What specific areas should be covered to ensure a complete, reflective report?

SAFETY



Do they have any symptoms which could cause a safety consideration?

Consider if someone is experiencing a relapse, the symptoms may include extreme fatigue and pain. This may cause limited concentration and difficulties safely managing activities.

TIMELY



For any activities where restriction is reported how long does it take them to complete these activities? Has how long it takes them changed over time?

If someone is experiencing fatigue, this may impact how long it takes them to complete activities. You must explore if completing something such as cooking, washing or dressing increases their symptoms and if this would take more than twice as long as someone without the condition to complete. Not just fatigue - having severe diarrhoea, abdominal pain or joint pain can also mean it takes significantly longer to get ready for work/school than other people

ACEPTABLE
STANDARD



How have they adapted to completing tasks over time – is this different to what might be considered 'normal'?

Consider that some of the questions you may be asking about the condition could be sensitive. This may lead to the claimant under reporting their restrictions. Do not take reported function at face value. You must sensitively explore if they are completing activities to an acceptable standard unaided. If not, how are they managing?

REPEATEDLY



Are they able to repeat a task as often as required? Is this the same every day?

If someone experiences pain or fatigue, they may be able to complete an activity once, or have one good day where they have more energy. However, they may then be extremely limited in function due to their condition. You must explore if they can repeat an activity as many times as is to be reasonably expected throughout the day.

Sensitivities & Lived Experience

What areas might they find difficult to mention or perhaps understate the impact of?

You must consider that one of the primary symptoms of someone with a bowel condition is incontinence. This can be an extremely sensitive subject to discuss with a claimant and should be managed professionally.

Furthermore, often people with these conditions have struggled for many years to obtain diagnosis. They may have undergone multiple tests and examinations prior to diagnosis.

Living with a life long debilitating condition can have a substantial impact on someone's mental health and how this limits their functional ability.

Remember to adequately explore any co-existing conditions individually.

REMEMBER: A high percentage of people with colitis experience symptoms out of the gut so please ensure you are adequately exploring these symptoms and how they impact function on the majority of days.

Customer Care

- ✓ Companions can often provide brilliant insight into someone's function if they have been living with the condition for a prolonged period of time.
- ✓ Do NOT make assumptions around the condition. Every case, symptoms and functional impact are different.
- ✓ Ensure regular breaks are offered if the claimant is reporting or presenting with fatigue.

Watch a video [HERE](#)
where two women talk
about living with Colitis



"Just because you can't see it doesn't mean that it's not hard every single day."

"I've really had to deal with the way that I talk to myself and the way that I prioritize my mental health. For so long I was so focused on my physical health that I almost didn't even recognize that I was not addressing my mental health. It took a physical disease to make me really treasure and take care of my mental health just as much as my physical health."

"I've lost friends that didn't understand it or didn't feel like they could meet me where I was at."

"It is not just a bad stomach ache"

"I've had to increase my tolerance for what is a background level of pain."

"You have to do a lot of mental work to flip the way you perceive it because otherwise it can really eat away at you."



Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 1: Preparing food

People with active disease may be restricted by abdominal pain, urgency and frequency of bowel movements, joint pain and extreme fatigue. People in remission may still experience fatigue which limits them in completing this activity.

Remember in PIP...

Can someone prepare and cook a simple meal for one? How long can they stand in the kitchen? Can they chop and peel vegetables? Can they lift pans? Does completing this activity increase pain or fatigue? How do they feel after the activity? How long does it take to recover?

Activity 2: Taking nutrition

People may be extremely limited in what they can eat or have difficulties maintaining a healthy weight due to their condition. In severe cases, they may have difficulties swallowing and require an adapted or soft diet or feeding tube. They also require liquid nutritional supplements.

Remember in PIP...

Can they chew, swallow and bring food to their mouth? Can they physically cut food? Do they have any aids to assist such as adapted cutlery? Can they eat solid food? Do they have any risk of choking? Can they complete this activity in a timely manner?

Activity 3: Managing therapy and monitoring a health condition

People with colitis may be receiving extensive therapy and treatment to manage their condition. They may require multiple hospital visits and planned/emergency admissions. They are likely to also be taking multiple oral medications

Remember in PIP...

Therapy is only considered within the scope of the activity if received in the home environment. If they do have therapy at home, do they require assistance? If so, why and how long does this take?

Regarding their medication, can they manage this themselves? Can they administer their own medication? Can they remember to take it and physically remove it from packaging?

Also, many medications for colitis are injected at home. Can they inject themselves? Do they need assistance with this?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 4: Washing and Bathing

People with active disease may be restricted by abdominal pain, urgency and frequency of bowel movements, joint pain and extreme fatigue. People in remission may still experience fatigue and other related symptoms which limits them in completing this activity. They may also need to bathe/shower more often than other people if they experience episodes of bowel incontinence

Remember in PIP...

You must explore how someone is managing the activity. How do they get in and out of the bath? Do they have any aids? Can they wash their entire body? How long does it take and how do they feel after? Does this activity increase their symptoms? How long does it take to recover? Do they need assistance with upper or lower body? Do they have fatigue or abdominal pain during or after this activity?

Activity 6: Dressing and undressing

People with active disease may be restricted by abdominal pain, urgency and frequency of bowel movements, joint pain and extreme fatigue. People in remission may still experience fatigue which limits them in completing this activity. Consider that they may need to undress quickly if they have urgent diarrhoea and therefore may have adapted the type of clothes/fastenings etc, they wear to accommodate this.

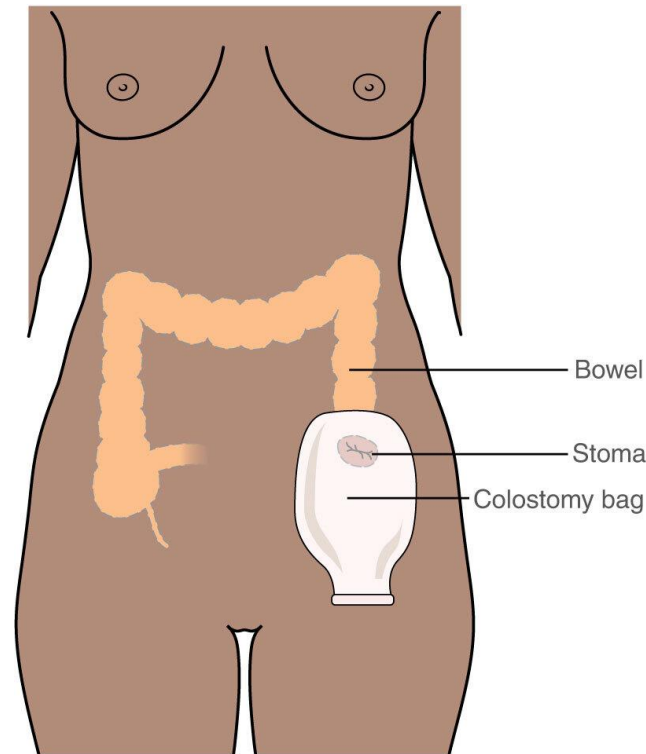
Remember in PIP...

You must explore someone's ability to dress and undress within the scope of STAR. How long does it take them? Can they dress upper and lower body? Does this increase symptoms of pain and/or fatigue? Do they require assistance or use any aids? Can they dress reliably whilst seated?

Activity 5 Managing toileting needs and incontinence

Ulcerative Colitis starts in the rectum in most cases. This causes a proctitis, which means inflammation of the rectum. In some cases it only affects the rectum and the colon is not affected. In others, the disease spreads up to affect some, or all, of the colon. Between flare-ups the inflamed areas of colon and rectum may heal and symptoms may go away. The severity of a flare-up can be classed as mild, moderate or severe:

- Mild** - you have fewer than four stools (faeces) daily and only have small amounts of blood in your stools. You do not feel generally unwell (no systemic disturbance).
- Moderate** - you have four to six stools a day, have some blood in your stools but do not feel generally unwell in yourself (no systemic disturbance).
- Severe** - you have more than six stools a day and have blood in your stools. You also feel generally unwell with more marked systemic disturbance with things such as high temperature (fever), a fast pulse rate, anaemia, etc.
- Around 10 in every 100 people with ulcerative colitis may need surgery ten years after diagnosis. The intestine is brought to the surface of the abdomen and an opening is made so that digestive waste drains into a bag, known as a stoma, rather than through the anus.**
- You must also remember that not all surgery results in a stoma**



Remember in PIP...

You must explore how someone gets onto and off the toilet and how they clean themselves. Does doing this cause any pain? We do not consider ability to mobilise to the toilet.

However, if someone has urgency, does this lead to incontinence? How many times a day are they emptying their bowels? If they have a stoma, how are they managing this? Can they do this independently?

Consider impact of manual dexterity on stoma care - especially if people who also have joint issues. This may mean it takes a long time or they require assistance to manage it reliably.

You can access a video [HERE](#) on stoma care to provide you with some insight into stoma management.

Activity 12 Moving Around

Remember in PIP...

You must explore STAR when asking about someone's ability to mobilise. It is not sufficient to simply indicate a distance or time someone can walk for.

Firstly establish when someone is walking, do they require an aid? If so, what aid? Was this prescribed or self purchased?

How far can they walk and how long does this take? How does walking make them feel? Does breathlessness/fatigue/joint pain increase each time they walk? When they walk a second time, does pace reduce or distance reduce? If they experience fatigue, how do they feel later in the day? How many times could they repeat the distance they walk? How long does it take to recover from mobilising?

Lived examples are also extremely beneficial. How do they manage up and down the stairs? How do they manage with chores? How do they manage their shopping? How many aisles can they walk and how long does it take? If they go to their GP surgery or hospital, how far is it from the car? How long does it take them to get to the required department and how far is this?

Functional Impact

Although UC itself may not impact these activities within the scope of the PIPAG, please ensure you explore any co-morbidities that might.

Activity 7: Communicating Verbally

Remember in PIP...

Consider the impact of fatigue on cognitive function.

Can someone express and understand both basic and complex verbal information? Who do they speak to? Can they use a mobile phone? Do they have any cognitive or sensory impairments that may impact their ability to complete this activity?

Activity 8: Reading and understanding signs and symbols

Remember in PIP...

Consider the impact of fatigue on cognitive function.

Can someone read and understand basic and complex written information? What do they read? Can they read a text message or a book? Did they gain any qualifications in education?

Activity 9: Engaging with others face to face

Remember in PIP...

Do they have anxiety as a result of their UC? Are they isolating themselves? If they do go out, who do they engage with on a regular basis? How do they feel meeting unfamiliar people? If they have anxiety with unfamiliar people, who can support them? Have they stopped engaging due to their physical symptoms? Are they isolated due to their inability to go out?

Functional Impact

Although UC itself may not impact these activities within the scope of the PIPAG, please ensure you explore any co-morbidities that might.

Activity 10: Budgeting

Remember in PIP...

You must explore someone's ability to manage both basic and complex budgeting. This would include how they manage their household budgets. How do they plan for future purchases? Would they understand change to expect in a small transaction? Is there area impacted by low mood or any cognitive impairments?

Activity 11: Planning and following a journey

Remember in PIP...

You must explore someone's ability to complete both familiar and unfamiliar journeys. If someone reports the presence of anxiety, probing questions should be asked around the potential of OPD. This would include what their symptoms are, how they manage them, if they had support could they complete journeys on the majority of days?

Furthermore, general questions such as ability to follow a diversion, ability to plan a journey, ability to use public transport. Remember, physical restrictions are not covered within the scope of Activity 11.

Additional reading or other resources

EXTERNAL

[Ulcerative colitis - NHS \(www.nhs.uk\)](http://www.nhs.uk)

[Tips For Living With Ulcerative Colitis \(crohnsandcolitis.com\)](http://crohnsandcolitis.com)

[7 Things No One Tells You About Life With Ulcerative Colitis | SELF](#)

[Ulcerative Colitis | Symptoms, Diagnosis and Treatment | Patient](#)

[Ulcerative colitis: 'I was going to the toilet up to 30 times a day' - BBC News](#)

[What is a stoma? | Macmillan Cancer Support](#)

[Jenna talks about In My Shoes – YouTube](#)

[Kevin talks about In My Shoes: 24 hours with Crohn's or Colitis – YouTube](#)

[ims_hcp_guide_final.pdf \(crohnsandcolitis.org.uk\)](#)

Version Control