# Creating bespoke information for Black communities

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**Knowledge and Information Editor**

# A bit of background…

- We want to be the go-to source of information for everyone affected by Crohn's and Colitis
- High quality and accessible health information plays a role in tackling health inequalities
- But who is our information currently reaching?
- Insights suggested we are under-reaching and underserving certain ethnicities
- This is important. Particularly in the context of health inequalities that already exist between white and global majority ethnic groups

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# Four phases

1. Scoping phase: March 2024
   - 4 representatives from Black led organisations reviewed our existing portfolio

# Scoping phase: what did we learn?

- Identified areas for improvement:

  - Increased representation and diversity in assets
  - Calling out health inequalities and acknowledging systemic racism
  - Partnership working and joint branding
  - Bespoke resources
  - How we understand being evidence based
  - Signposting

Kohlrabi

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    - 1x survey (81 respondents)
    - 3x focus groups (12 participants)

# Gathering insights: what did the research tell us?

## Format

- Preference for written information

- Hybrid approach
  - Integrate information in existing resources, while also creating standalone resources specific to Black audiences

- Available in multiple languages

## Content

- Highlight lived experience, and improve personalisation
- Include topics such as ethnic specific manifestations, food, mental health and empowerment
- Feature Black healthcare professionals

# Gathering insights: what did the research tell us?

## Specific challenges highlighted by participants

- Fighting stigma and isolation
- Explaining symptoms to family and friends
- Finding support groups
- Bias and racism
- Healthcare professionals not understanding their needs
- Accessing appointments

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    - Two rounds of feedback on the draft resource

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# Creating the information: what did we produce?

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CROHN'S DISEASE
Your Guide

CROHN'S & COLITIS UK

ULCERATIVE COLITIS
Your Guide

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FOOD
Eating with Crohn's or Colitis

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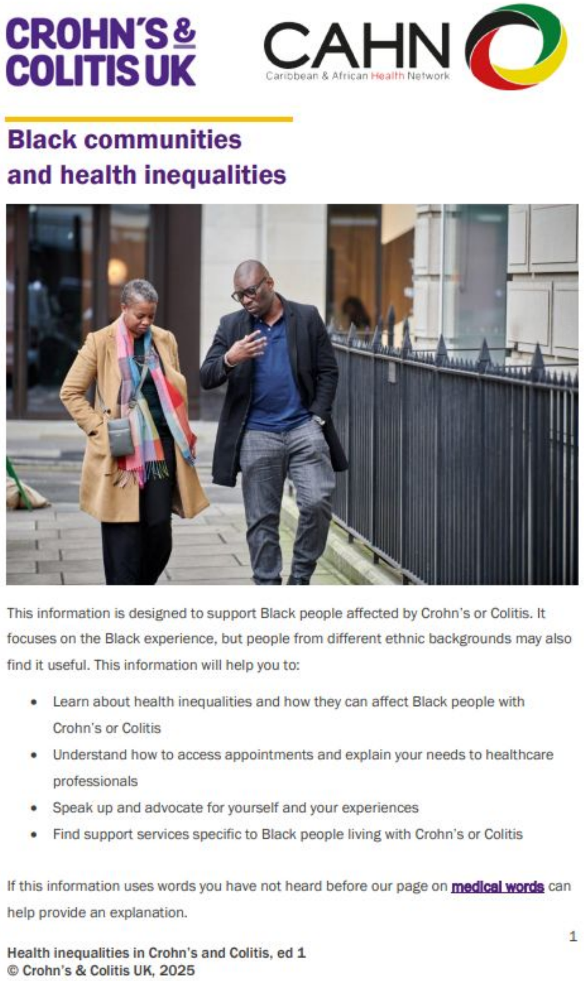
## Bones

Last updated: April 2025
Last full review: October 2023
Next review date: October 2026



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## Black communities and health inequalities

This information is designed to support Black people affected by Crohn's or Colitis. It focuses on the Black experience, but people from different ethnic backgrounds may also find it useful. This information will help you to:

- Learn about health inequalities and how they can affect Black people with Crohn's or Colitis
- Understand how to access appointments and explain your needs to healthcare professionals
- Speak up and advocate for yourself and your experiences
- Find support services specific to Black people living with Crohn's or Colitis

If this information uses words you have not heard before our page on medical words can help provide an explanation.

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Health inequalities in Crohn's and Colitis, ed 1
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## ABOUT CROHN'S & COLITIS UK

Crohn's & Colitis UK is a national charity, leading the fight against Crohn's and Colitis.

We're here for you whenever you need us. From treatment options to symptoms, relationship concerns to employment issues, our information can help you manage your condition.

Visit **crohnsandcolitis.org.uk/information** for all our information or scan the QR code below.

**Helpline service**
Our helpline service can also help provide support. Find out more at **crohnsandcolitis.org.uk/helpline** or call **0300 222 5700**.

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Last review: March 2025
Next review: March 2028

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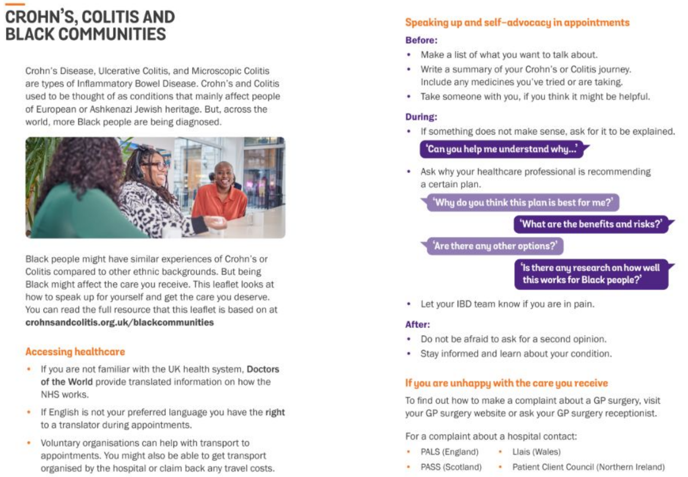
Caribbean & African Health Network
Greater Manchester CIC

## YOUR HEALTH, YOUR VOICE

CROHN'S, COLITIS AND BLACK COMMUNITIES

The content of this leaflet was informed by Black people living with Crohn's or Colitis, Black healthcare professionals, and the Caribbean & African Health Network (CAHN).



## CROHN'S, COLITIS AND BLACK COMMUNITIES

Crohn's Disease, Ulcerative Colitis, and Microscopic Colitis are types of Inflammatory Bowel Disease. Crohn's and Colitis used to be thought of as conditions that mainly affect people of European or Ashkenazi Jewish heritage. But, across the world, more Black people are being diagnosed.

Black people might have similar experiences of Crohn's or Colitis compared to other ethnic backgrounds. But being Black might affect the care you receive. This leaflet looks at how to speak up for yourself and get the care you deserve. You can read the full resource that this leaflet is based on at **crohnsandcolitis.org.uk/blackcommunities**

### Accessing healthcare

- If you are not familiar with the UK health system, **Doctors of the World** provide translated information on how the NHS works.
- If English is not your preferred language you have the **right** to a translator during appointments.
- Voluntary organisations can help with transport to appointments. You might also be able to get transport organised by the hospital or claim back any travel costs.

### Speaking up and self-advocacy in appointments

**Before:**

- Make a list of what you want to talk about.
- Write a summary of your Crohn's or Colitis journey. Include any medicines you've tried or are taking.
- Take someone with you, if you think it might be helpful.

**During:**

- If something does not make sense, ask for it to be explained.

'Can you help me understand why...'

- Ask why your healthcare professional is recommending a certain plan.

'Why do you think this plan is best for me?'

'What are the benefits and risks?'

'Are there any other options?'

'Is there any research on how well this works for Black people?'

- Let your IBD team know if you are in pain.

**After:**

- Do not be afraid to ask for a second opinion.
- Stay informed and learn about your condition.

### If you are unhappy with the care you receive

To find out how to make a complaint about a GP surgery, visit your GP surgery website or ask your GP surgery receptionist.

For a complaint about a hospital contact:

- PALS (England)
- PASS (Scotland)
- Llais (Wales)
- Patient Client Council (Northern Ireland)

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4. Disseminating the resource: March 2025 – April 2025
    - Week of advertising on social media, in collaboration with CAHN
    - Health webinar hour on Saturday 19th April
    - CAHN will be sharing printed leaflets at in-person events and health screenings

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# Thank you for listening.

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