

MANAGEMENT OF FATIGUE IN IBD



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Disclosures Consulting fees, honoraria/lecture fees: AbbVie, Abivax, Arena, Astra Zeneca, BMS, Celltrion, Falk, Galapagos, GSK, Janssen, J&J, MSD, Pfizer, Pharmacosmos, Takeda, Roche, Eli Lilly



TREATING THE WHOLE PATIENT

"You treat my anxiety; you're treating my Crohn's!
You treat my fatigue and low mood; you're treating my Crohn's!
You treat my eyes; you're treating my Crohn's!
You treat my self esteem; you're treating my Crohn's
and that will treat me as a whole.

**BUT *THEY'RE* ONLY LOOKING AT ONE ASPECT OF IT,
AND THEY MISS IT COMPLETELY."**

(woman with Crohn's Disease)

66 99



WHAT IS FATIGUE?

- **Extreme tiredness** that does not go away with the usual amount of rest or sleep
- **Can be unpredictable.** Energy levels may change from day to day, or even hour to hour
- For some people, it **may come on quickly.** You may do too much of an activity, and when you stop the fatigue suddenly comes on.
- But fatigue **can also build up very slowly,** so slowly that you do not notice it. This can make it hard to tell what's normal for you.



WHAT IS FATIGUE?

- **Fatigue is a frequently experienced symptom in IBD, by...**
 - 7 in 10 people with "active" disease¹
 - 4 in 10 people with "inactive" disease (in remission)^{2,3}
- People report fatigue as **one of the most debilitating symptoms**⁴
A 2023/24 Crohn's & Colitis UK survey of 1,680 people affected by IBD found fatigue to be the thing that had the biggest impact on quality of life.
- People find it **difficult to talk about fatigue**⁵
- People report that fatigue is not addressed in clinics⁵



66 99

I'LL BE FUNCTIONING IN WHAT I CONSIDER TO BE A PERFECTLY NORMAL WAY AND FEELING GREAT ONE MINUTE, AND THE NEXT MINUTE, FOR NO REASON WHATSOEVER, I'LL SUDDENLY DRAIN AND HAVE NO ENERGY.

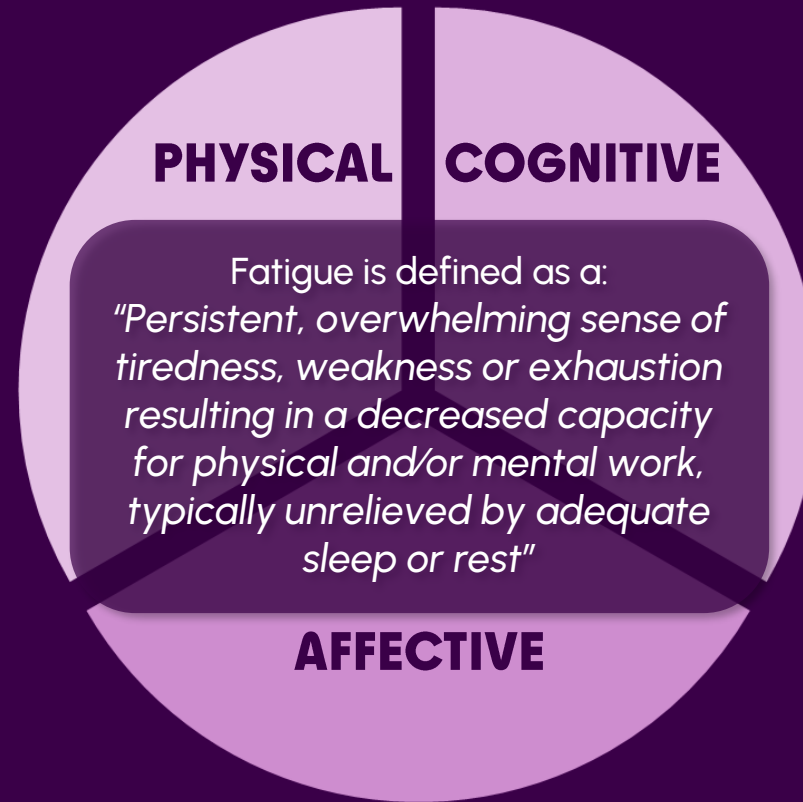
Fatigue in IBD study participant



TYPES OF FATIGUE

Subjective: Weakness, perceived inability to initiate or complete tasks, tiredness

Objective: Measurable decrease in physical activity and/or performance with repeated or prolonged activity



Subjective: Difficulty concentrating, thinking clearly

Objective: Measurable decrease in cognitive function or performance (e.g. memory) with repeated/prolonged testing

Subjective only: Decreased motivation, low mood, no energy



REPORTED IMPACTS OF FATIGUE

PHYSICAL:

work, sleeping, physical exercise, driving, finance, gender role, hobbies, interests

PSYCHOLOGICAL/EMOTIONAL:

frustration, isolation, motivation, attitude, freedom, confidence, self-esteem, depression, relationships

IMPACT OF FATIGUE

COGNITIVE:

memory, concentration, speech, mixing up words, education, learning

SOCIAL:

family, travel, holidays, prejudice, hobbies, interests, social situations



FATIGUE: A RESEARCH PRIORITY

What Are the Top 10 Research Questions in the Treatment of Inflammatory Bowel Disease? A Priority Setting Partnership with the James Lind Alliance

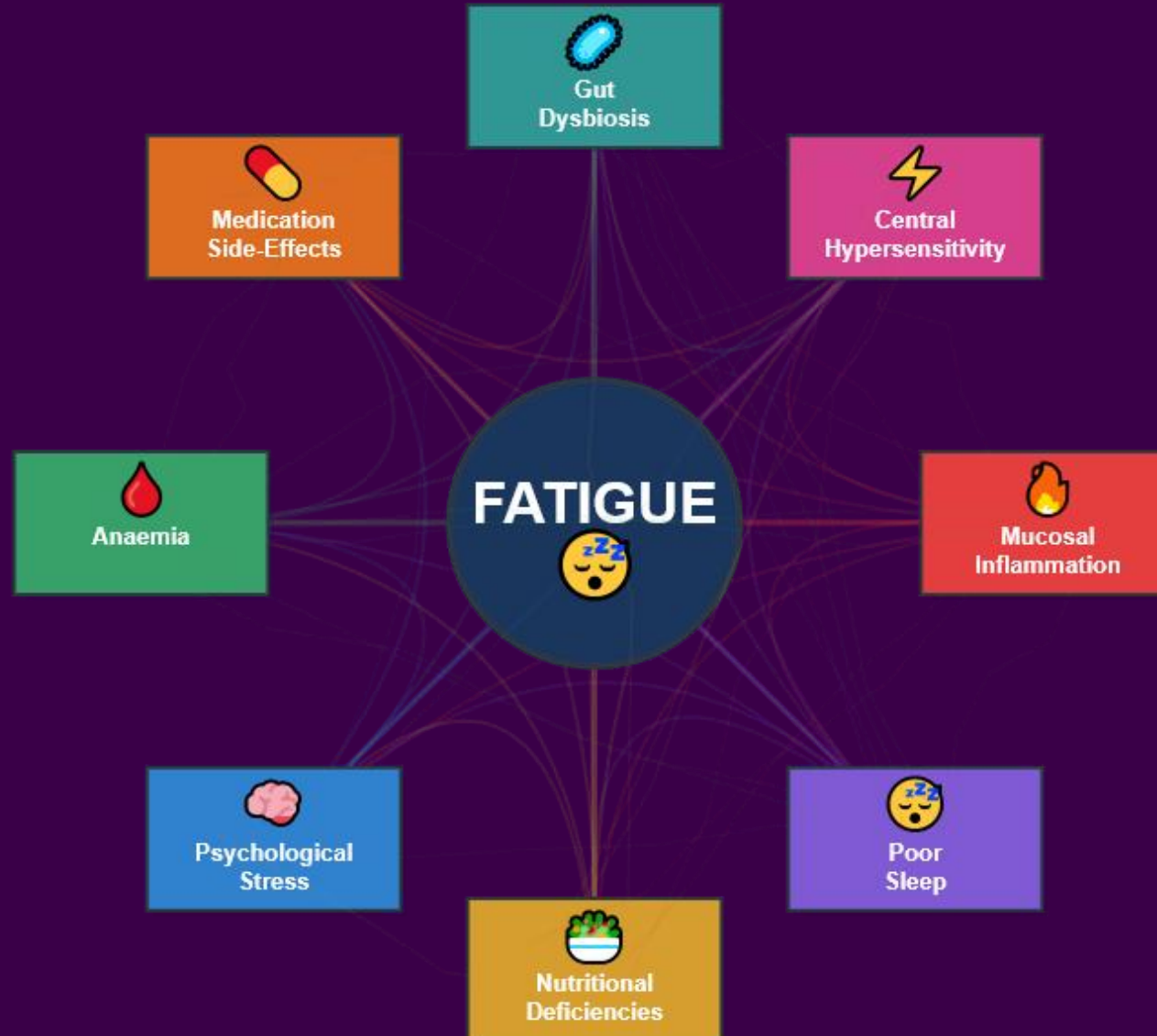
Ailsa L. Hart,^a Miranda Lomer,^b Azmina Verjee,^c Karen Kemp,^d Omar Faiz,^a Ann Daly,^e Julie Solomon,^f John McLaughlin^g

Inflammatory Bowel Disease Top 10

1. What is the optimal treatment strategy considering efficacy, safety and cost-effectiveness (immunomodulators, biologics, surgery, combinations) in IBD management: selecting the right patient group, right stage of disease, and assessing potential for withdrawal?
2. What are the optimal markers/ combinations of markers (clinical, endoscopic, imaging, genetics, other biomarkers) for stratification of patients with regards to a) disease course and b) monitoring disease activity and c) treatment response?
3. What role does diet have in the management of mildly active or inactive ulcerative colitis or Crohn's Disease to achieve normal daily activities and symptom control?
4. How can pain be most effectively managed in people with IBD?
5. What is an optimal treatment strategy for perianal Crohn's Disease and what individual factors determine this?
6. What is the best treatment for controlling diarrhoea and/or incontinence symptoms in people with IBD, including novel pharmacological and non-pharmacological options? Is high-dose Loperamide safe and effective in the treatment of diarrhoea in IBD?
7. What is the optimal dietary therapy (liquid enteral diet and/or reintroduction diet) and duration to achieve mucosal healing in active IBD and/or remission either as a primary or adjunctive treatment? Is there a difference between adults and children?
8. What is the association between IBD and fatigue and how should it be managed?
9. Does early surgery or later surgery for terminal ileal Crohn's disease result in better outcomes (quality of life, cost-effectiveness)?
10. Does influencing the gut microbiota influence the course of IBD?



WHAT MIGHT CAUSE FATIGUE?

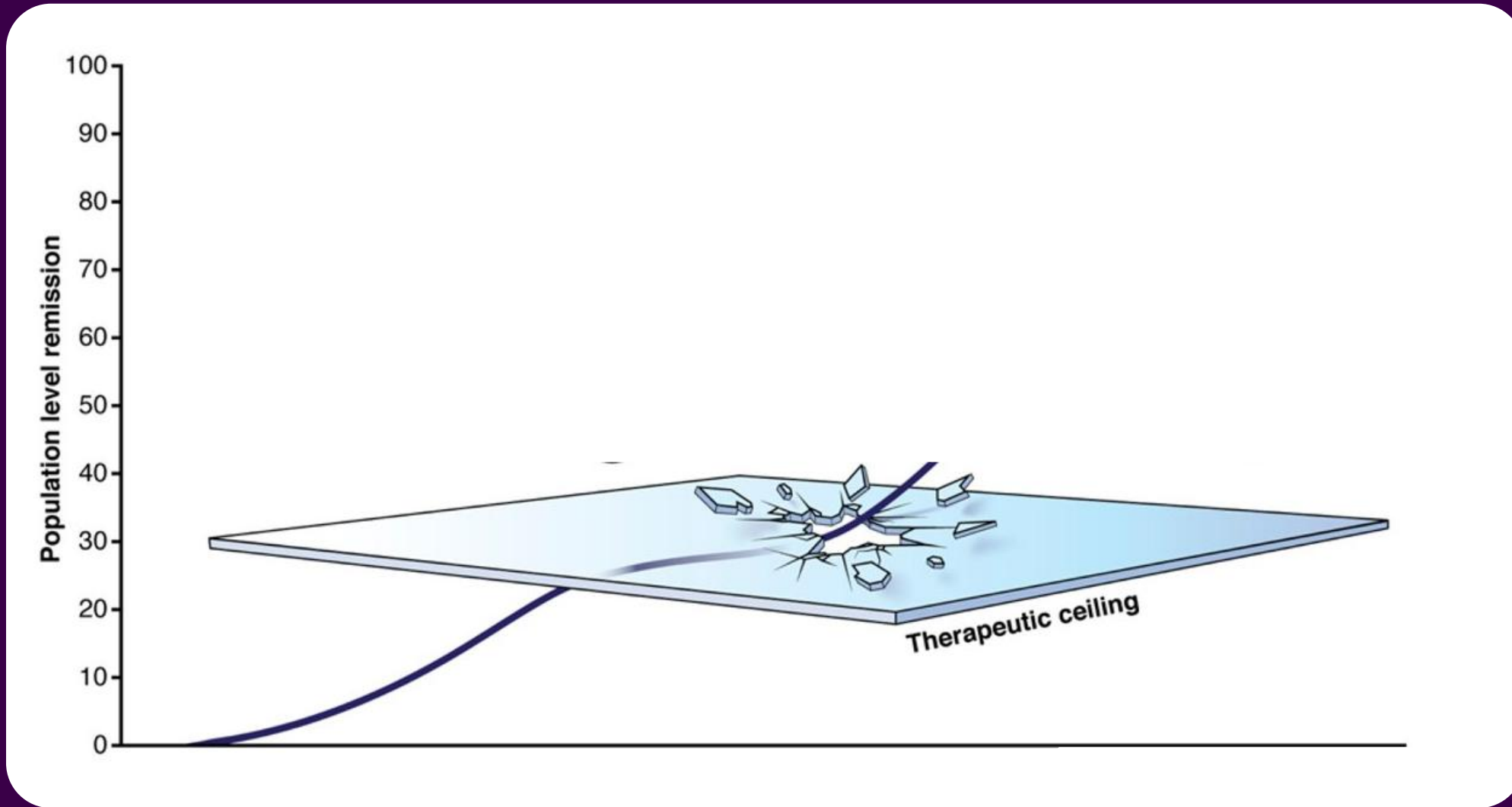


**HITTING THE TARGET OF
INFLAMMATION
IS CENTRAL**



A graphic featuring a target with three concentric white rings on a purple background. A pink dart with a black and white striped shaft is shown hitting the center bullseye. A white rectangular box with rounded corners is overlaid horizontally across the middle of the target.

...but there are several problems...



...many patients do not have resolution of inflammation...





...and even if we do achieve resolution of inflammation...

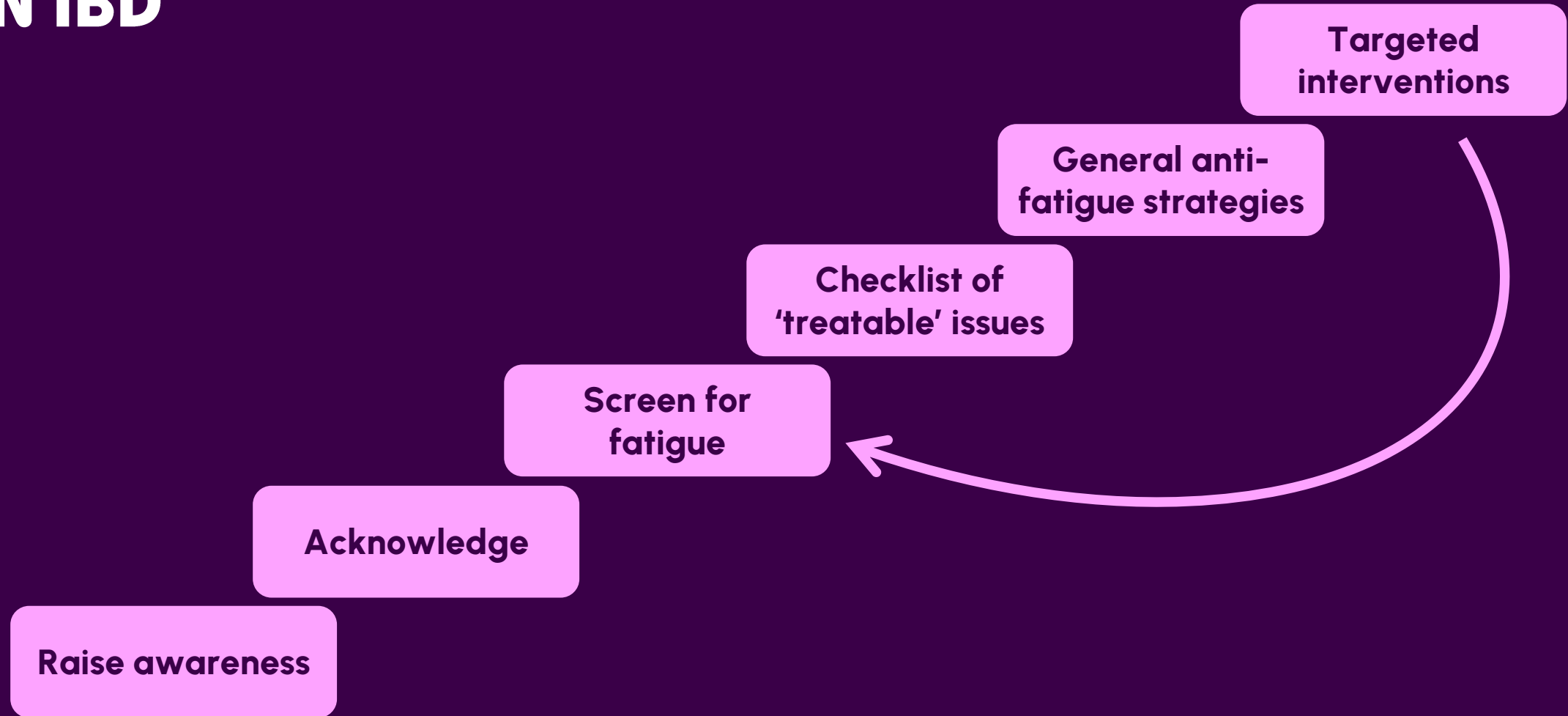




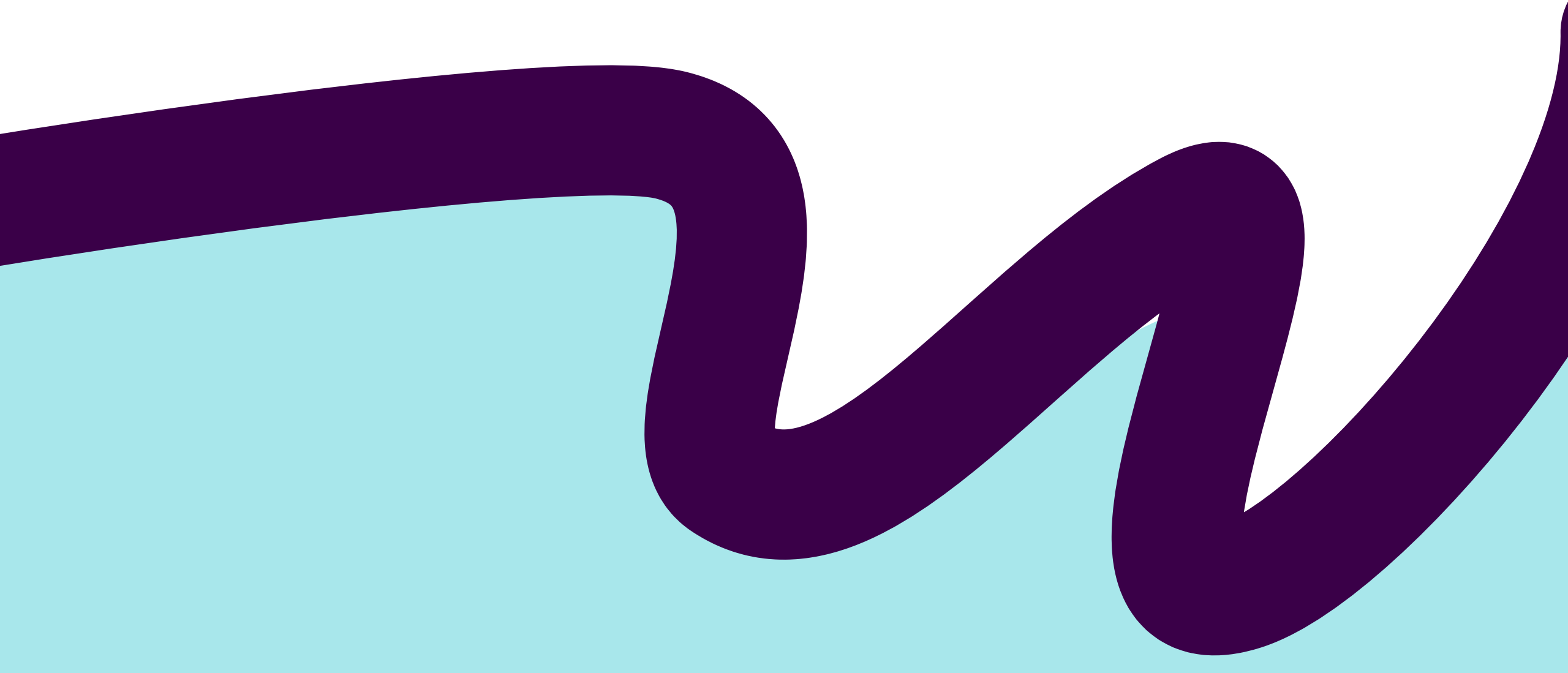
>50% fatigue
>50% chronic pain
25-30% anxious / depressed



SIX STEPS TO MANAGEMENT OF FATIGUE IN IBD



ASSESSING FATIGUE



IBD FATIGUE SCALE (IBD-F)

crohnsandcolitis.org.uk/fatigue-scale

Section 1 - Fatigue Assessment Scale (5 questions)

+

Section 2 - IBD-Fatigue impact on Daily Activities Scale (30 questions)

+

EMAIL A COPY OF YOUR RESULTS

Enter your email address below to have your results sent to you.

These could also be useful to your GP or healthcare professional during an appointment.

Email address

EMAIL RESULTS



IBD FATIGUE SCALE (IBD-F)

crohnsandcolitis.org.uk/fatigue-scale

What does your score mean?

0

You don't have fatigue

1 - 10

You have slight to moderate fatigue and we suggest you seek medical advice

11 - 20

Fatigue has a severe affect on your daily activities and we suggest you see a specialist

IF YOU SCORED 1 OR MORE IN SECTION 1, PLEASE CONTINUE TO SECTION 2

This section assesses the perceived impact of fatigue on your daily activities in the past two weeks.

The possible answers to this question are:
0: None of the time, 1: Some of the time, 2: Often, 3: Most of the time, 4: All of the time.
If a particular activity does not apply to you, for example you do not drive, please select N/A.

Section 2: IBD-Fatigue Impact on Daily Activities Scale (20 questions)

1. I had to nap during the day because of fatigue
 0 1 2 3 4

2. Fatigue stopped me from going out to social events
 0 1 2 3 4

3. I was not able to go to work or college because of fatigue
 0 1 2 3 4

4. My performance at work or education was affected by fatigue
 0 1 2 3 4

5. I had problems concentrating because of fatigue
 0 1 2 3 4

6. I had difficulty motivating myself because of fatigue
 0 1 2 3 4

7. I could not wash and dress myself because of fatigue
 0 1 2 3 4

8. I had difficulty with walking because of fatigue
 0 1 2 3 4

9. I was unable to drive as much as I need to because of fatigue
 0 1 2 3 4

10. I was not able to do as much physical exercise as I wanted to because of fatigue
 0 1 2 3 4

11. I had difficulty continuing with my hobbies/interests because of fatigue
 0 1 2 3 4

12. My emotional relationship with my partner was affected by fatigue
 0 1 2 3 4

13. My sexual relationship with my partner was affected by fatigue
 0 1 2 3 4

14. My relationship with my children was affected by fatigue
 0 1 2 3 4

15. I was low in mood because of fatigue
 0 1 2 3 4

16. I felt isolated because of fatigue
 0 1 2 3 4

17. My memory was affected because of fatigue
 0 1 2 3 4

18. I made mistakes because of fatigue
 0 1 2 3 4

19. Fatigue made me irritable
 0 1 2 3 4

20. Fatigue made me frustrated
 0 1 2 3 4

21. I got words mixed up because of fatigue
 0 1 2 3 4

27. I had difficulties sleeping at night because of fatigue
 0 1 2 3 4

28. Fatigue affected my ability to do all my normal household activities
 0 1 2 3 4

29. I had to ask others for help because of fatigue
 0 1 2 3 4

30. Quality of my life was affected by fatigue
 0 1 2 3 4

You must answer all the required questions in section 2 to view your score.



CHECKLIST FOR FATIGUE

Have these tests been done?

Active inflammation is one of the most likely causes of fatigue. One or more of the following tests should have been done to exclude active disease. If inflammation is active, this should be treated and then fatigue level re-assessed.

1. MRI Scan

YES

NO

2. Colonoscopy

YES

NO

3. Faecal Calprotectin

YES

NO

4. Disease index

YES

NO

5. CRP

YES

NO



Have these blood tests been done?

Abnormalities of blood chemistry or micronutrients may be causing or contributing to fatigue. It is worth considering if any of the following are addressed if abnormal.

1. Haemoglobin

YES NO

2. Ferritin

YES NO

3. Vitamin D

YES NO

4. Testosterone

YES NO

5. Thyroid Function

YES NO

6. Vitamin B12

YES NO

7. Folate

YES NO

8. Magnesium

YES NO

9. Sodium

YES NO

10. Potassium

YES NO

11. Cortisol

YES NO

12. CRP

YES NO

13. Calcium

YES NO

14. Albumin

YES NO

15. Glucose

YES NO

16. Zinc

YES NO

17. Selenium

YES NO

Are any of these conditions present?

Many different conditions can cause or contribute to fatigue. It is worth considering if any of the following are present.

1. Depression or low mood

YES NO

2. Liver disease

YES NO

3. Rheumatoid Arthritis

YES NO

4. HIV

YES NO

5. Medication

YES NO

6. Coeliac Disease

YES NO

7. Weight loss

YES NO

8. Nutritional deficiencies

YES NO

9. Anxiety

YES NO

10. Grief

YES NO

11. Disease related factors

YES NO

12. Alcohol abuse

YES NO

13. Drug abuse

YES NO

14. Work related stress

YES NO

15. Family stress

YES NO

16. Overexertion

YES NO

17. Inactivity

YES NO



CHECKLIST FOR FATIGUE

**Is there
inflammation?**

**Are the "tanks"
full?
Especially
nutrition, vitamin
deficiencies,
anaemia?**

**Are there
comorbidities/
other causes of
fatigue/EIMs:
especially mental
health?**



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CHECKLIST FOR FATIGUE

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MENTAL HEALTH AND FATIGUE

- **Anxiety, depression, and stress** have all been associated with fatigue in people with Crohn's and Colitis
- Often, they are seen together, so it's **hard to know if they are causes of fatigue or the result of fatigue**
- Stress can trigger inflammation, pain and difficulty sleeping
- **These symptoms may also add to fatigue**



TALKING ABOUT FATIGUE

Whoever you want to talk to and whatever you want them to know - you're in the right place. We've got the words to help break the ice.

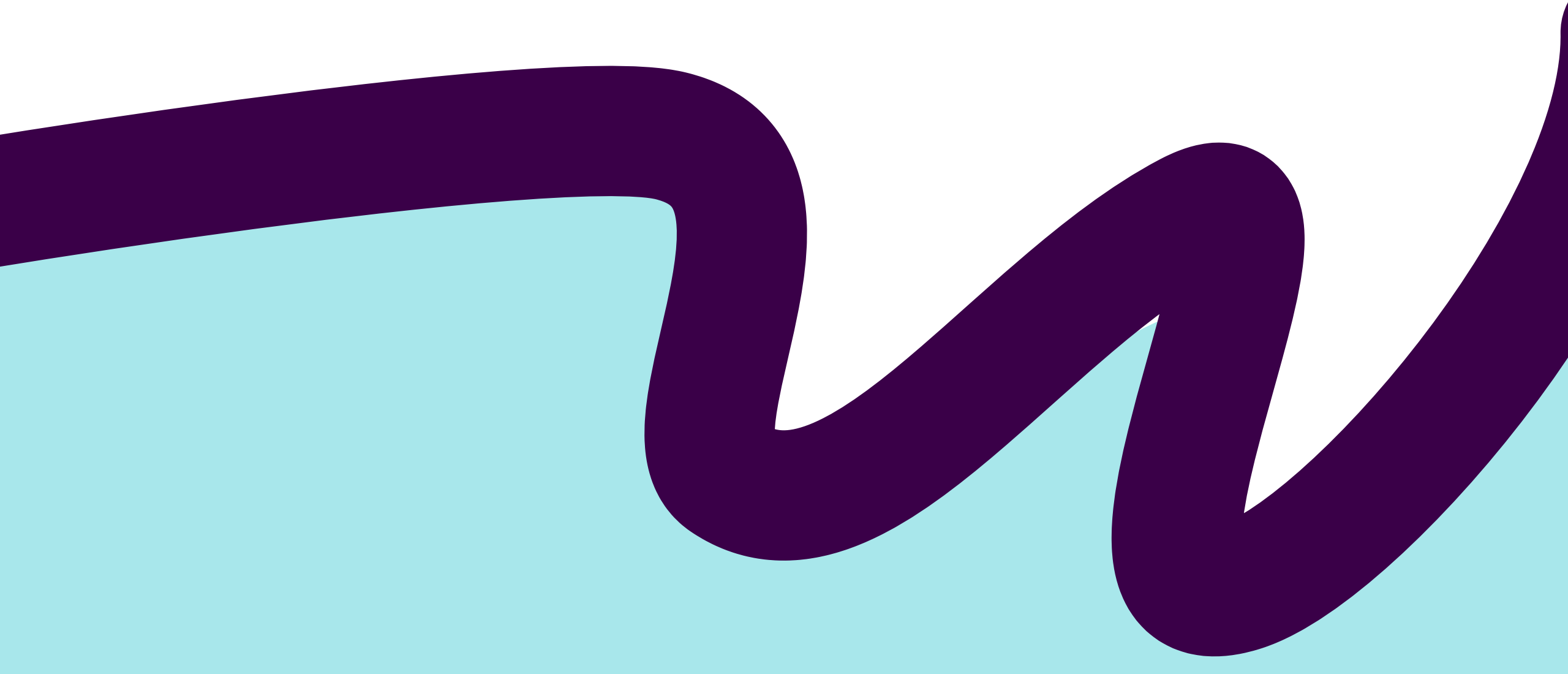
Just answer five questions to get your own personalised talking toolkit - which will have all the information, talking tips and resources you'll need to feel confident to start your conversation.

[CREATE YOUR TALKING TOOLKIT](#)

crohnsandcolitis.org.uk/talkingtoolkit



TREATING FATIGUE



KEY QUESTION TO ASK IS...



...do you sleep?



FATIGUE WITH INSOMNIA

Non- pharmacological

- Minimise alcohol and caffeine
- Regular waking time and avoid daytime sleeping
- Increase 'pressure' on sleep through increased activity during the day and sunlight exposure
- Graded exercise

Pharmacological

- Mirtazapine (15mg at night for insomnia only, 30-45mg if depressed) and assess in 2-3 months
- Avoid benzodiazepines



FATIGUE WITHOUT INSOMNIA

Avoid boom-and-bust
cycles*, plan, prioritise, pace

If appropriate, use non-
sedative antidepressant, e.g.
SSRI, SNRI or vortioxetine


Promising medications
(for specialist initiation)

Bupropion

Modafinil



CAN ADVANCED THERAPIES HELP FATIGUE?



Contents lists available at [ScienceDirect](#)


Digestive and Liver Disease

journal homepage: www.elsevier.com/locate/dld

Alimentary Tract

Change in fatigue in patients with ulcerative colitis or Crohn's disease initiating biologic therapy

Edouard Louis^{a,*}, Peter Bossuyt^b, Arnaud Colard^c, Antoine Nakad^d, Didier Baert^e, Fazia Mana^f, Philip Caenepeel^g, Stijn Vanden Branden^h, Severine Vermeireⁱ, Francois D'Heygere^j, Beatrijs Strubbe^k, Anneline Cremer^l, Vida Setakhr^m, Filip Baertⁿ, Anne Vijverman^o, Jean-Louis Coenegrachts^p, Frederic Flamme^q, Anke Hantson^r, Jie Zhou^s, Geert Van Gassen^f



Clinical Trial > [J Crohns Colitis](#). 2024 Nov 4;18(11):1804-1818.
doi: 10.1093/ecco-jcc/jjae083.

Impact of Upadacitinib Induction and Maintenance Therapy on Health-related Quality of Life, Fatigue, and Work Productivity in Patients with Moderately-to-severely Active Crohn's Disease

Subrata Ghosh¹, Brian G Feagan^{2,3}, Rogério Serafim Parra⁴, Susana Lopes⁵, Adam Steinlauf⁶, Yoichi Kakuta⁷, Namita Joshi⁸, Wan-Ju Lee⁸, Ana P Lacerda⁸, Qian Zhou⁸, Si Xuan⁸, Kristina Kligys⁸, Nidhi Shukla⁸, Edouard Louis⁹

Research into biologic treatments and their effect on fatigue

Some show improvements in fatigue levels – but important to remember that decisions about treatment options are highly individualised and take into account many different factors.

Impact of mirikizumab treatment on fatigue in patients with moderately to severely active Crohn's disease: results from the phase 3 VIVID-1 study

Miguel Regueiro^{1,10}, Monika Fischer², Peter Bossuyt³, Marijana Protic⁴, Kristina Traxler⁴, Guanglei Yu⁴, Huaiyu Zang⁵, Aisha Vadhariya⁴, Tadakazu Hisamatsu⁶, Pascal Juillerat^{7,8}, Alessandro Armuzzi^{9,10}, Javier P. Gisbert¹¹, Alissa Walsh¹²



IBD BOOST



Prof Ailsa Hart

Prof Rona Moss-Morris

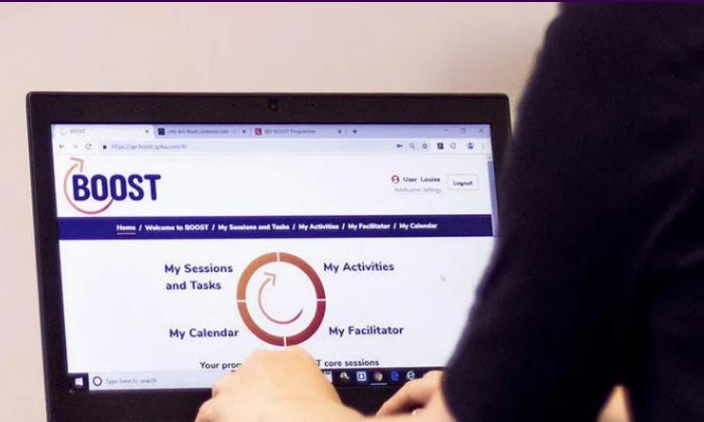
Prof Christine Norton



The IBD-BOOST Survey

The IBD-BOOST Survey aims to describe the inter-relationship of the symptoms, their prevalence and associations with quality of life, depression, anxiety, disease activity, disease history and demographic and lifestyle factors.

[IBD-BOOST Survey](#)



The IBD-BOOST Optimise Study

IBD-BOOST Optimise is a non-randomised experimental study to test the effectiveness of a checklist and nurse-led algorithm for identifying and treating medical causes of IBD-related symptoms of fatigue, pain and urgency.

[IBD-BOOST Optimise](#)



The IBD-BOOST TRIAL

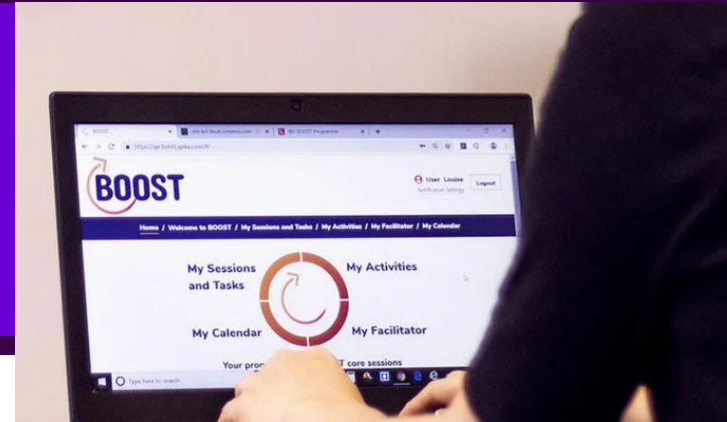
A randomised control trial of an interactive online symptom management programme with nurse support. The 'BOOST' programme has been designed by psychologists at King's College London as well as people with IBD and based on the principles of cognitive behavioural therapy.

[IBD-BOOST Trial](#)



IBD BOOST

In 8,486 patients: over **50%** reported faecal incontinence; **30%** reported fatigue and **21%** reported pain *in the last week*; many had **multiple 'vicious circles' of interacting symptoms**; depression and anxiety are under diagnosed (over 50% reported depression and anxiety; only 25% had known 'diagnosed' mental health disorders)³⁻⁵



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[IBD-BOOST Optimise](#)



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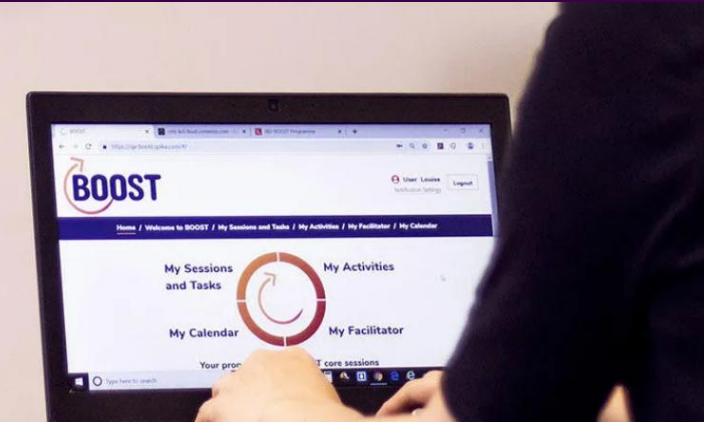
Doing the basics well: IBD nurse-led structured assessment and management algorithm for fatigue, pain, and continence; 3% had 'red flags' picked up; 35% needed 'optimizing'



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A randomised control trial of an interactive online symptom management programme with nurse support. The 'BOOST' programme has been designed by psychologists at King's College London as well as people with IBD and based on the principles of cognitive behavioural therapy.

IBD-BOOST Trial



IBD BOOST INTERVENTION

BOOST

User Louise
Notification Settings Logout

Home / Welcome to BOOST / My Sessions and Tasks / My Activities / My Facilitator / My Calendar

My Sessions and Tasks
My Activities
My Calendar
My Facilitator

Your progress on the BOOST core sessions

100%

Active session

Summary and maintaining improvement - Continue your active session >

Core sessions

<p>Session 1: Understanding your IBD symptoms <i>Task: symptom diary</i></p>	<ul style="list-style-type: none"> • Factors that can contribute to fatigue, pain and urgency in IBD • Identifying factors that relate to you • Use of self-monitoring not symptom focusing • Setting your aims for the programme
<p>Session 2: Balancing your activity, eating and exercise <i>Task: reviewing goals for activity + sleep diary</i></p>	<ul style="list-style-type: none"> • Importance of activity & exercise • How fear leads to avoidance • Eating patterns • Setting your goals for activity and exercise
<p>Session 3: Improving your sleep <i>Task: reviewing goals for sleep</i></p>	<ul style="list-style-type: none"> • Why is sleep important? • Sleep patterns & habits • Improving your sleep • Setting your goals for sleep
<p>Session 4a: Changing your thoughts: Part 1 <i>Task: thought record</i></p>	<ul style="list-style-type: none"> • Why are thoughts important? • Identifying unhelpful thinking
<p>Session 4b: Changing your thoughts: Part 2 <i>Task: alternative thought record</i></p>	<ul style="list-style-type: none"> • Developing alternative thoughts
<p>Session 5: Managing stress and coping with emotions <i>Task: Reviewing goals for stress + stress diary</i></p>	<ul style="list-style-type: none"> • The effects of stress and finding ways to manage it • The role of emotions and determining how best to take care of yourself • Setting your goals for managing stress and emotions
<p>Session 6: Making the most of your social support and communication <i>Task: Reviewing goals for social support</i></p>	<ul style="list-style-type: none"> • Types of social support • Communication and disclosure • Setting your goals for social support

Facilitator support of digital self-management

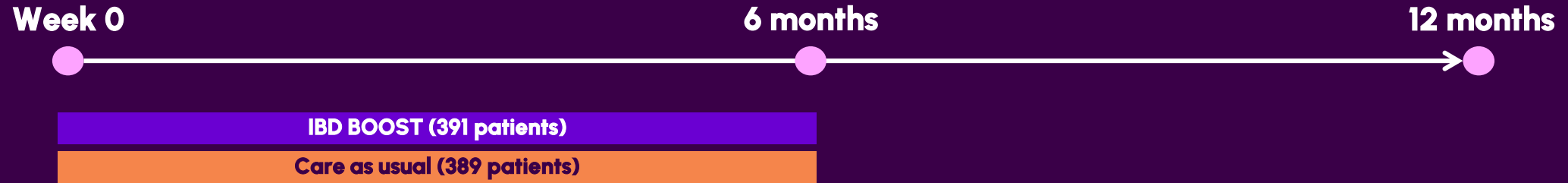
- 8 core sessions
- 4 symptom-specific sessions

Pain in IBD

- 7) Managing and Understanding Pain in IBD
- 8) The Role of Acceptance and Self-Compassion in Pain
- 9) Summary and Maintaining Improvement



IBD BOOST TRIAL DESIGN



Total 780 patients

Patient population:

- IBD patients ≥ 18 years of age
- Participated in IBD BOOST survey
- Rated impact of at least one of the 3 symptoms (fatigue, pain, FI/urgency) ≥ 5 on 11-point symptoms scale (i.e. 0-10)
- Desired help for symptoms
- No red flags

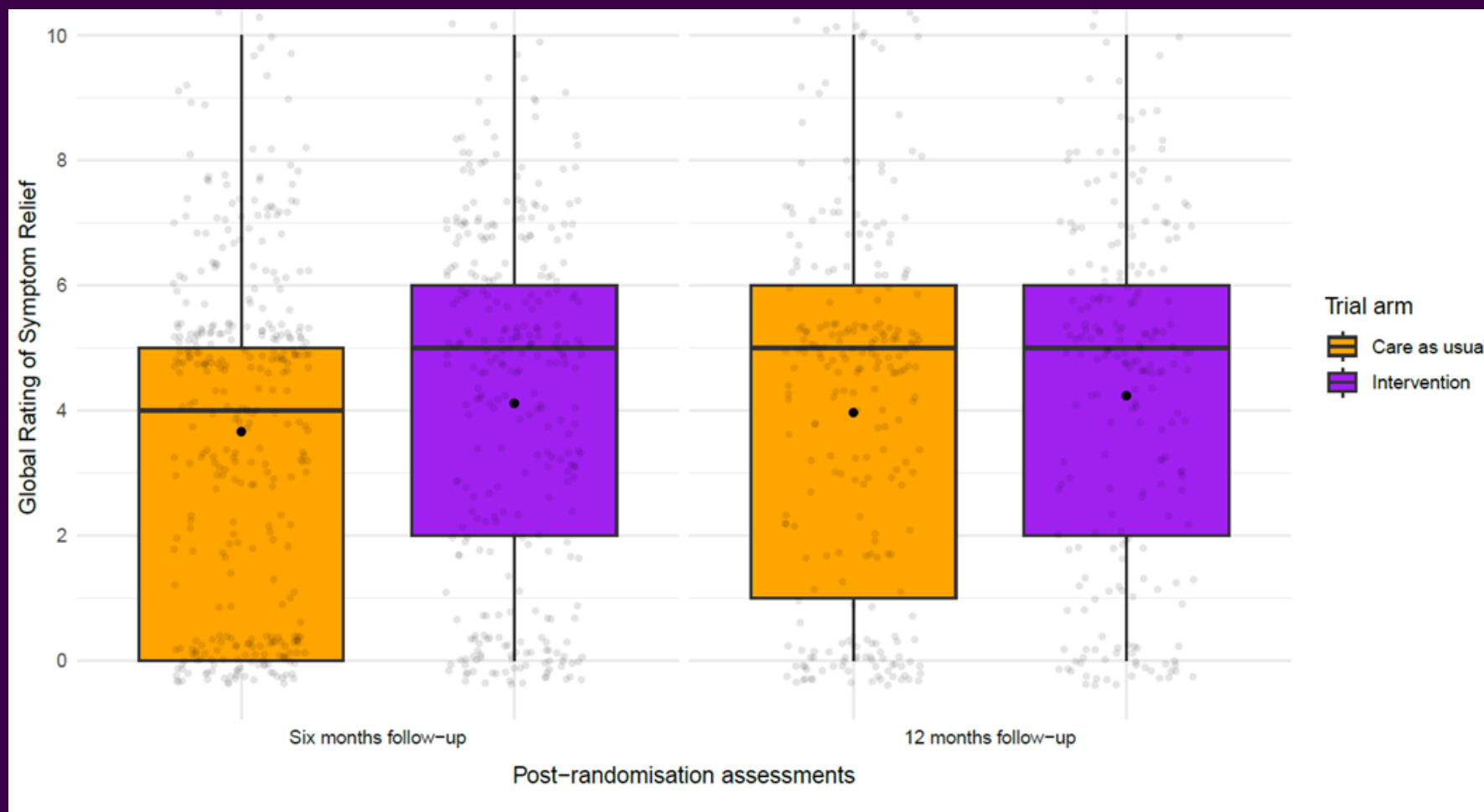
Primary outcome: at 6 months i) UK-IBDQ ii) global rating of symptom relief (GRSR)
Secondary outcomes: included individual symptom scores, EQ-5D-5L

FUNDED BY

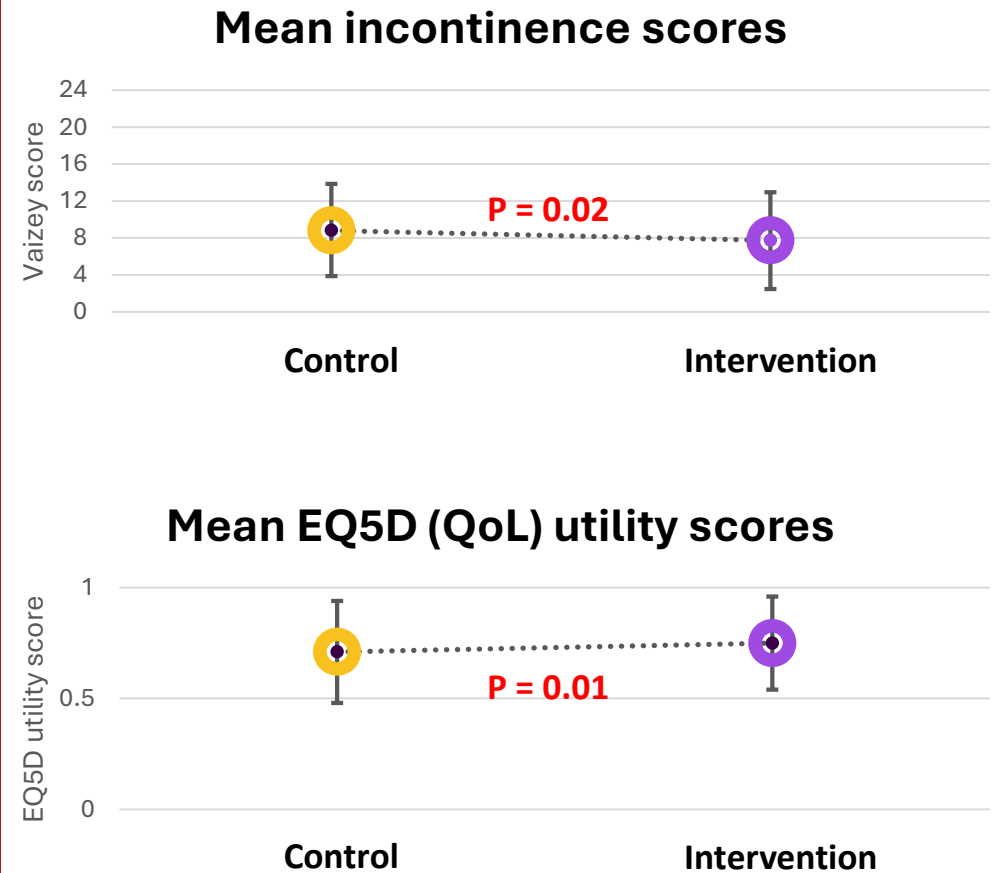
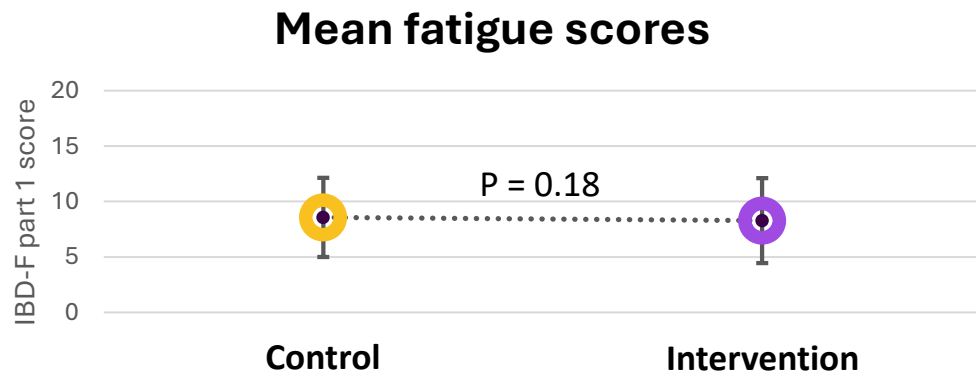
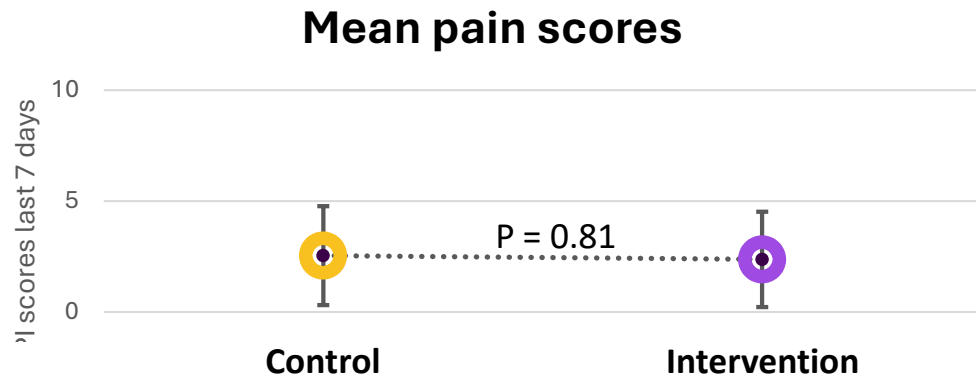
NIHR | National Institute for
Health and Care Research



RESULTS: IBD BOOST PRIMARY OUTCOME (GLOBAL RATING OF SYMPTOM RELIEF SCORES)



RESULTS: IBD BOOST SECONDARY OUTCOMES (AT 6 MONTHS)



IBD BOOST CONCLUSIONS

Learnings, challenges, successes and what's next

- No significant difference in UK-IBDQ or Global Rating of Symptom Relief Scores between the IBD BOOST intervention compared with the control group
- At 6 months, the IBD BOOST group reported improvement in general health-related quality of life, compared with the control group
- People who complied with the IBD BOOST intervention reported better UK-IBDQ scores than 'would-be' compliers in the control group
- The IBD BOOST intervention was found to be cost-effective



FATIGUE TAKEAWAYS

CROHN'S &
COLITIS UK



It's like being hit in the face with a wave of heaviness.

crohnsandcolitis.org.uk/fatigue

