IBD BOOST
Living well with Crohn's & Colitis

IBD-BOOST SURVEY (for office use only)						
SITE ID:						
PARTICIPANT ID:						
CRF BOOKLET NUMBER:						

IBD-BOOST: SURVEY

Note: Please answer this survey whether or not you have symptoms of fatigue pain or urgency. It is really important for the research that we have people without symptoms to compare with those who do have them. We are aware that there is some duplication of questions as some of the questionnaires we are using ask the same things. Please fill in ALL questions, even if you feel that you have already answered the same thing in this survey. Thank you.

Please send this back in the stamped addressed envelope provided [to be added to postal version only]

Part 1: Contact Details

The information collected in this part of the survey will be used to confirm who has completed this survey. If you have consented, we will also use it for contact on future research.

1. First Name

2. Surname

3. Mobile or home phone number

4. Email Address

IF YOU ARE INTERESTED IN BEING PART OF RELATED RESEARCH, PLEASE GIVE BOTH AN EMAIL ADDRESS AND A PHONE NUMBER

Postal Address

5. House or flat number or name

6. Address line 1

7. Address line 2 (optional)

8. Town/City

9. Postcode

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SITE ID:					
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10. How do you currently receive your IBD care (Crohn's or Colitis):

I am with a hospital for my IBD *(go to Question 11)* ☐

I am not currently with a hospital, only a GP *(Go to Question 12)* ☐

I am not currently with a hospital, and not registered with a GP *(Go to Question 12)* ☐

11. Are you currently receiving care for your IBD (Crohn's or Colitis) from any of the following NHS Hospitals? *please tick your main hospital only*

	Please tick one only
Barnsley Hospital NHS Foundation Trust *(Barnsley Hospital)*	☐
Barts Health NHS Trust *(Royal London Hospital)*	☐
Blackpool Teaching Hospitals NHS Foundation Trust *(Blackpool Victoria Hospital)*	☐
Cambridge University Hospitals NHS Foundation Trust *(Addenbrooke's Hospital)*	☐
Chelsea and Westminster Hospital NHS Foundation Trust *(Chelsea and Westminster Hospital)*	☐
Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust *(Doncaster Royal Infirmary or Mexborough Montague Hospital or Bassetlaw District Hospital)*	☐
Dorset County Hospital NHS Foundation Trust *(Dorset County Hospital)*	☐
Hull University Teaching Hospitals NHS Trust *(Hull Royal Infirmary or Castle Hill Hospital)*	☐
London North West University Hospital NHS Trust *ST MARK'S HOSPITAL & Northwick Park Hospital*	☐
London North West University Hospital NHS Trust *(EALING HOSPITAL)*	☐
Mid and South Essex Hospitals NHS trust *(Broomfield Hospital)*	☐
Nottingham University Hospitals NHS Trust *(Queens Medical Centre or City Hospital)*	☐
The Queen Elizabeth Hospital King's Lynn NHS Foundation Trust *(The Queen Elizabeth Hospital, King's Lynn)*	☐
The Rotherham NHS Foundation Trust *(Rotherham Hospital)*	☐
Royal Cornwall Hospitals NHS Trust *(Royal Cornwall Hospital)*	☐
Royal Devon and Exeter NHS Foundation Trust *(Royal Devon and Exeter Hospital)*	☐
Salford Royal *(Salford Royal Hospital)*	☐
Sheffield Teaching Hospitals NHS Foundation Trust *(Royal Hallamshire Hospital)*	☐
St George's University Hospitals NHS Foundation Trust *(St George's Hospital)*	☐

List of hospitals Continued on next page

Question 11. Continued.

Please tick one only

St Helens and Knowsley Teaching Hospitals NHS Trust *(Whiston Hospital* or St Helen's Hospital) ☐

Torbay and South Devon NHS Foundation Trust *(Torbay Hospital)* ☐

United Lincolnshire Hospitals NHS Trust *(Lincoln County Hospital or Louth Hospital or John Coupland or Hospital Grantham Hospital)* ☐

Warrington and Halton Teaching Hospitals NHS Foundation Trust *(Warrington Hospital or Halton General Hospital)* ☐

Other Hospital not on the list above:

12. Please write the date you are completing this survey (DD / MMM / YYYY)

D	D

M	M	M

Y	Y	Y	Y

PLEASE GO TO PART 2: YOUR IBD AND YOUR HEALTH

Part 2: Your IBD and your health

1. Which of the following have you been diagnosed with? *please tick one only*

☐ Crohn's disease or Crohn's colitis

☐ Indeterminate Colitis, IBD Unclassified or other type of IBD.

☐ Ulcerative colitis

☐ Not sure

2. In what year was your IBD diagnosis confirmed?

☐☐☐☐

3a. Have you ever had an operation (of any sort) for your IBD?

Yes ☐ No ☐

3b. If yes, number of operations: ☐

4. Do you have a stoma right now? Yes ☐ No ☐

5. Do you have an ileo-anal pouch right now? Yes ☐ No ☐

6. Do you have an anal fistula right now? Yes ☐ No ☐ Unsure ☐

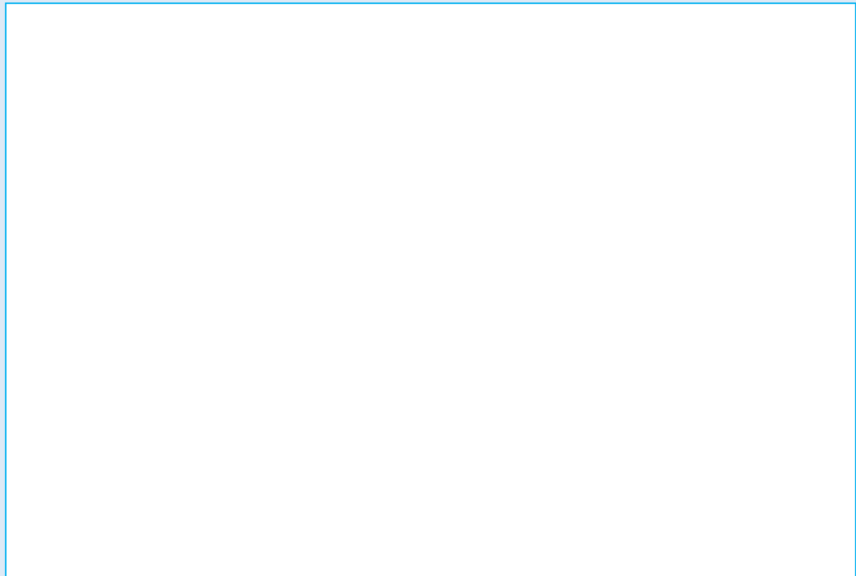
7. Have you taken any of the following medications for your IBD? tick once for each item

	Taking now	Not now but taken in the past	Never taken	Unsure if taken
7(a) Aminosalicylates / 5ASA by mouth (e.g. *Asacol, Mesalazine*, *Pentasa, Octasa, Mezavant, Salofalk, Balsalazide)*	☐	☐	☐	☐
7(b) Aminosalicylates / 5ASA as an enema or suppository (e.g. *Asacol foam, Pentasa suppository, Salofalk foam)*	☐	☐	☐	☐
7(c) Azathioprine or **mercaptopurine** (*e.g. Imuran, Azafalk, , 6-MP*)	☐	☐	☐	☐
7(d) Steroids as an enema or suppository (e.g. *Predfoam, Colifoam*, *Prednisolone suppository*)	☐	☐	☐	☐
7(e) Methotrexate by mouth or as an injection	☐	☐	☐	☐
7(f) Infliximab (*Remicade, Remsima, Inflectra*) as an infusion	☐	☐	☐	☐
7(g) Vedolizumab (*Entyvio*) as an infusion	☐	☐	☐	☐
7(h) Golimumab (*Simponi*) as an injection	☐	☐	☐	☐
7(i) Adalimumab *(Humira*) as an injection or infusion	☐	☐	☐	☐
7(j) Ustekinumab (*Stelara*) as an injection or infusion	☐	☐	☐	☐
7(k) Other medication but I don't know the name	☐	☐	☐	☐
7(l) Steroids by mouth (e.g. *Prednisolone, Budesonide, Entocort*)	☐	☐	☐	☐

8. If you have Steroids by mouth; have you had more than 3 courses of steroids in the past year OR had difficulty coming off steroids? Yes ☐ No ☐ N/A ☐

9. Other medication for IBD you are taking NOW

please write the name



10. Other medication for IBD you are NOT taking now but have taken in the past year

please write the name

11. Are you pregnant? *please tick one only*

Yes ☐ No ☐ Unsure ☐ N/A ☐

12. Have you ever been medically diagnosed with any of the following conditions?
please tick all that apply

- ☐ Heart problems
- ☐ Cancer (any type)

If yes, which type of cancer:

- ☐ Thyroid problems
- ☐ Kidney problems
- ☐ Diabetes
- ☐ Respiratory problems (breathing problems, including asthma)
- ☐ Liver disease
- ☐ Anxiety or depression treated by medication, therapy or counselling in the past year
- ☐ Other mental health illness (e.g. schizophrenia or bi-polar disorder)
- ☐ Major neurological or nerve problems (such as multiple sclerosis)
- ☐ Any other major illness or disease *(Please list below)*

- ☐ None of the above

Part 3: Symptoms:

PLEASE COMPLETE THESE SECTIONS EVEN IF YOU DON'T EXPERIENCE THESE SYMPTOMS.

(A) Fatigue

Fatigue is tiredness that doesn't usually get better following rest or sleep.

1. Overall how would you rate your IBD-related fatigue *(Please circle one number only)*

0	1	2	3	4	5	6	7	8	9	10
No fatigue at all										**Worst imaginable fatigue**

2. Overall how much impact does fatigue have on your life? *(Please circle one number only)*

0	1	2	3	4	5	6	7	8	9	10
None at all										**Has a major impact on my life**

Fatigue. *Please respond to each question by circling one answer per row.*

In the past 7 days . . .

	Never	*Rarely*	*Sometimes*	*Often*	*Always*
3. How often did you feel tired?	1	2	3	4	5
4. How often did you experience extreme exhaustion?	1	2	3	4	5
5. How often did you run out of energy?	1	2	3	4	5
6. How often did your fatigue limit you at work (include work at home)?	1	2	3	4	5
7. How often were you too tired to think clearly?	1	2	3	4	5
8. How often were you too tired to take a bath or shower?	1	2	3	4	5
9. How often did you have enough energy to exercise strenuously?	5	4	3	2	1

10. If there was help available for IBD-related fatigue, would you be interested?

A) Definitely ☐ B) Possibly ☐ C) No ☐

(B) Pain assessment

1. Overall how would you rate your IBD-related pain. *Please circle one number only*

0	1	2	3	4	5	6	7	8	9	10

No pain at all — **Worst imaginable pain**

2. Overall how much impact does IBD-related pain have on your life? *Please circle one number only*

0	1	2	3	4	5	6	7	8	9	10

None at all — **Has a major impact on my life**

3. If you have IBD-related pain is this: Please tick one only

- Abdominal (belly) pain only ☐
- Non-Abdominal (non-belly) pain only ☐
- Both belly & non-belly pain ☐
- I do not have IBD related pain ☐

Pain Intensity – Scale. *Please respond to each question by circling one answer per row.*

In the past 7 days . . . .

	Had no pain	*Mild*	*Moderate*	*Severe*	*Very severe*
4. How intense was your pain at its worst?	***1***	***2***	***3***	***4***	***5***
5. How intense was your average pain?	***1***	***2***	***3***	***4***	***5***

	No Pain	*Mild*	*Moderate*	*Severe*	*Very severe*
6. What is your level of pain right now?	**1**	**2**	**3**	**4**	**5**

	Never	*Rarely*	*Sometimes*	*Often*	*Always*
7. Do you take pain medication for IBD pain?	***1***	***2***	***3***	***4***	***5***

8. If you take medication for IBD pain, please write the one you most usually take.

9. If there was help available for IBD-related pain, would you be interested?

A) Definitely ☐ B) Possibly ☐ C) No ☐

(C) Urgency, leakage and bowel control

IF YOU HAVE A STOMA PLEASE GO TO PART 4: Your IBD Control.

***1. Overall how would you rate your IBD-related* urgency and bowel control?** *Please circle one number only*

0	1	2	3	4	5	6	7	8	9	10

No problem with urgency or bowel control at all — **Worst imaginable urgency and bowel control**

2. Overall how much impact does IBD-related urgency and bowel control have on your life? *Please circle one number only*

0	1	2	3	4	5	6	7	8	9	10

None at all — **Has a major impact on my life**

Please respond to each question by circling one answer per row.
In the past 7 days . . . .

	No days	*1 day*	*2-3 days*	*4-5 days*	*6-7 days*
3. How often did you have bowel incontinence—that is, have an accident because you could not make it to the toilet in time?	***1***	***2***	***3***	***4***	***5***
4. How often did you soil or stain your underwear before getting to a toilet?	***1***	***2***	***3***	***4***	***5***
5. How often did you leak stool or soil your underwear?	***1***	***2***	***3***	***4***	***5***

	Never	*Rarely*	*Sometimes*	*Often*	*Always*
6. How often did you think you were going to pass gas, but stool or liquid came out instead?	**1**	**2**	**3**	**4**	**5**

	Never	*Rarely*	*Sometimes*	*Often*	*Always*
7. Do you need to wear a pad/plug/ or change underwear for soiling?	***1***	***2***	***3***	***4***	***5***
8. Are you taking constipating medicines? (such as Imodium / loperamide / codeine)	***1***	***2***	***3***	***4***	***5***
9. Are you unable to hang on for 15 minutes after you feel the need to find a toilet?	***1***	***2***	***3***	***4***	***5***

10. If there was help available for IBD-related urgency and bowel control, would you be interested?

A) Definitely ☐ B) Possibly ☐ C) No ☐

Part 4: Your IBD control

Do you believe that:	Yes	No	Not Sure
1. Your IBD has been well controlled in the past two weeks?	☐	☐	☐
2. Your current treatment is useful in controlling your IBD?	☐	☐	☐
(if you are not taking any treatment, please click this box)		☐	

	Better	No Change	Worse
3. Over the past 2 weeks, have your bowel symptoms been getting worse, getting better or not changed?	☐	☐	☐

In the past 2 weeks, did you:	Yes	No	Not Sure
4. Miss any planned activities because of IBD? (e.g. attending school/college, going to work or a social event)	☐	☐	☐
5. Wake up at night because of symptoms of IBD?	☐	☐	☐
6. Suffer from significant pain or discomfort?	☐	☐	☐
7. Often feel lacking in energy? (fatigued) (by 'often' we mean more than half of the time)	☐	☐	☐
8. Feel anxious or depressed because of your IBD?	☐	☐	☐
9. Think you needed a change to your treatment?	☐	☐	☐

10. How would you rate the OVERALL control of your IBD in the past two weeks?
(Please circle one number only)

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Worst Possible Control										Best Possible Control

Part 5: Your IBD Activity

If you have a stoma or ileo-anal pouch, please go to section 6: Quality of life.

If you have CROHN'S DISEASE or CROHN'S COLITIS, please complete this section.

1. Please write the number of liquid stools or very soft stools for each of the past 7 days. *Please write a number for each day, write 0 if you did not have any*

DAY						
1	*2*	*3*	*4*	*5*	*6*	*7*

2. Abdominal Pain (over last 7 days). *Please write in each day*

0 = none, 1 = mild, 2 = moderate, 3 = severe

DAY						
1	*2*	*3*	*4*	*5*	*6*	*7*

If you have ULCERATIVE COLITIS, INDETERMINATE COLITIS or UNCLASSIFIED IBD, please complete this section.

1. Stool Frequency based on the past 3 days. Please tick one only

- ☐ Normal number of stools
- ☐ 1-2 stools more than normal
- ☐ 3-4 stools more than normal
- ☐ 5 or more stools more than normal

2. Rectal Bleeding based on the past 3 days. Please tick one only

- ☐ No blood seen
- ☐ Streaks of blood with stool less than half the time
- ☐ Obvious blood with stool most of the time
- ☐ Blood alone passed

Part 6: EQ-5D-5L

*Under each heading, please tick the **ONE** box that best describes your health **TODAY***

MOBILITY

I have no problems in walking about ☐

I have slight problems in walking about ☐

I have moderate problems in walking about ☐

I have severe problems in walking about ☐

I am unable to walk about ☐

SELF-CARE

I have no problems washing or dressing myself ☐

I have slight problems washing or dressing myself ☐

I have moderate problems washing or dressing myself ☐

I have severe problems washing or dressing myself ☐

I am unable to wash or dress myself ☐

USUAL ACTIVITIES (*e.g. work, study, housework, family or leisure activities*)

I have no problem doing my usual activities ☐

I have slight problems doing my usual activities ☐

I have moderate problems doing my usual activities ☐

I have severe problems doing my usual activities ☐

I am unable to do my usual activities ☐

PAIN / DISCOMFORT

I have no pain or discomfort ☐

I have slight pain or discomfort ☐

I have moderate pain or discomfort ☐

I have severe pain or discomfort ☐

I have extreme pain or discomfort ☐

ANXIETY / DEPRESSION

I am not anxious or depressed ☐

I am slightly anxious or depressed ☐

I am moderately anxious or depressed ☐

I am severely anxious or depressed ☐

I am extremely anxious or depressed ☐

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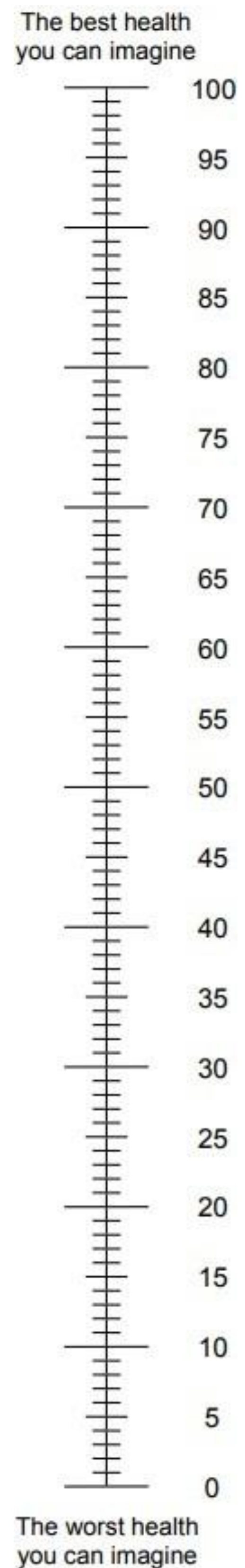
- **We would like to know how good or bad your health is TODAY.**
- **This scale is numbered from 0 to 100.**
- **100 means the best health you can imagine.**
  0 means the worst health you can imagine.
- **Mark an X on the scale to indicate how your health is TODAY.**
- **Now, please write the number you marked on the scale in the box below.**

YOUR HEALTH TODAY = ☐



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Part 7. How are you feeling

Over the last 2 weeks, how often have you been bothered by the following problems? *Please respond by circling the answer that most applies.*

	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	***0***	***1***	***2***	***3***
2. Not being able to stop or control worrying	***0***	***1***	***2***	***3***
3. Worrying too much about different things	***0***	***1***	***2***	***3***
4. Trouble relaxing	***0***	***1***	***2***	***3***
5. Being so restless that it is hard to sit still	***0***	***1***	***2***	***3***
6. Becoming easily annoyed or irritable	***0***	***1***	***2***	***3***
7. Feeling afraid as if something awful might happen	***0***	***1***	***2***	***3***

8. If you circled any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
☐	☐	☐	☐

Over the <u>last 2 weeks</u>, how often have you been bothered by any of the following problems? *Please circle a number for each*

	Not at all	Several days	More than half the days	Nearly every day
9. Little interest or pleasure in doing things	*0*	*1*	*2*	*3*
10. Feeling down, depressed, or hopeless	*0*	*1*	*2*	*3*
11. Trouble falling or staying asleep, or sleeping too much	*0*	*1*	*2*	*3*
12. Feeling tired or having little energy	*0*	*1*	*2*	*3*
13. Poor appetite or overeating	*0*	*1*	*2*	*3*
14. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	*0*	*1*	*2*	*3*
15. Trouble concentrating on things, such as reading the newspaper or watching television	*0*	*1*	*2*	*3*
16. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	*0*	*1*	*2*	*3*
17. Thoughts that you would be better off dead or of hurting yourself in some way	*0*	*1*	*2*	*3*

If you are concerned about anxiety or depression, the helplines at the end of the survey can offer expert advice.

Part 8. About you: Note: we are collecting this information so that we can compare people with and without symptoms of fatigue, pain and urgency

1. Gender. *please tick one only*

Female ☐ Male ☐ Prefer not to say ☐

Prefer to self-describe (please write) ________

2. ***Age in years***

☐☐

3. Which of the following best describes your ethnicity? *(please tick one only)*

A White	
English/ Welsh/ Scottish/ Northern Irish/British	
Irish	
Gypsy or Irish Traveller	
Any other White background	

D Black or Black British	
Black/Black British - Caribbean	
Black/Black British – African	
Any other Black Background	

B Mixed	
White and Black Caribbean	
White and Black African	
White and Asian	
Any other mixed background	

E Other Ethnic Groups	
Arab	
Latin American	
Any other ethnic group*	

C Asian or Asian British	
Indian	
Pakistani	
Bangladeshi	
Chinese	
Any other Asian background/ Asian British	

F Other	
Not known	
Prefer not to say	

* If other please state: ________

4. Your height

☐ feet ☐☐ Inches **OR** ☐☐☐ CM

5. Your weight

☐☐ stone ☐☐ lbs **OR** ☐☐☐ KG

6. Which of the following best describes your main work activity? *please tick one only*

- ☐ Employed Full Time
- ☐ Employed Part Time
- ☐ Student
- ☐ Retired
- ☐ Unemployed
- ☐ Self-employed
- ☐ Homemaker
- ☐ Unemployed due to illness/disability

7. What is the HIGHEST level of education you have completed? *please tick one only*

- ☐ No formal education
- ☐ Secondary school (GCSE)
- ☐ Sixth form (AS/A-levels)
- ☐ Further Education (Vocational courses / apprenticeships / diplomas)
- ☐ Higher Education – University Degrees

8. Relationship Status? *please tick one only*

- ☐ Married/Civil partnership
- ☐ Living with partner
- ☐ Widowed
- ☐ Divorced / separated
- ☐ Single
- ☐ With a partner (but not living together)

Part 9. Lifestyle

1. Do you smoke?

A) Never smoked ☐ B) Ex-smoker ☐ C) Current smoker ☐

2. If you are a current smoker, how many cigarettes do you smoke a day?

☐☐

3. How many units of alcohol do you drink during an average week?

A unit of alcohol is equal to: ½ a pint of ordinary beer, lager or cider; 1 single measure of spirits; 1 small glass of wine; or 1 measure of fortified wine (*please tick one answer only)*

None ☐ 1-14 units ☐ 15 or more units ☐

Thank You!

If you are completing this questionnaire on paper, please send using the stamped addressed envelope to:

IBD-Boost Programme
Florence Nightingale Faculty of Nursing and Midwifery

James Clerk Maxwell Building,
57 Waterloo Road,
London SE1 8WA

Phone: 020 7848 3318

email: IBD-BOOST@KCL.ac.uk

Support for physical and mental health

If you need support for physical or mental health don't suffer in silence, get help. You could:

- *Contact your local IBD service at your hospital (many have a Helpline)*
- *Contact your GP*
- *or call the NHS non-emergency number:* ***111 (****24 hours a day)* ***www.nhs.uk***

Support with your IBD

Crohn's & Colitis UK
Support is available from your care team and organisations like Crohn's and Colitis UK if you need it. ***www.crohnsandcolitis.org.uk***

Crohn's & Colitis Support Line: ***0121 737 9931***
(13:00 -15:30 Tuesday to Thursday, and 18:30 - 21:00 Monday to Friday)

Support for mental health

If you are concerned about anxiety or depression, these helplines can offer expert advice.

Mind
Promotes the views and needs of people with mental health problems.

Phone: ***0300 123 3393*** *(Mon-Fri, 9am-6pm)*

Website: ***www.mind.org.uk***

Samaritans
Confidential support for people experiencing feelings of distress or despair.

Phone: ***116 123*** *(free 24-hour helpline)*

Website: ***www.samaritans.org***