Thank you for completing this questionnaire.

If you have any general comments about your digestive or bowel treatment, or this questionnaire, please write them below.

Once you have completed the questionnaire please return it in the FREEPOST envelope provided, or send it to

ENIGMA Study Team
Swansea Clinical School
University of Wales Swansea
Singleton Park
Swansea
SA2 8PP

If you have any concerns about your symptoms please consult your GP or hospital doctor.

YOUR COMMENTS

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Study Number

Evaluating Innovations in Gastroenterology for the NHS Modernisation Agency (ENIGMA) study

Baseline Questionnaire

A questionnaire for people with digestive and bowel disorders

Please complete this questionnaire at home as soon as you have time and return to us using the prepaid envelope enclosed.

PLEASE DO NOT WAIT UNTIL YOU RECEIVE YOUR APPOINTMENT TO COMPLETE THIS.

CONFIDENTIAL

Please read all the instructions before completing this questionnaire.

Thank you for agreeing to take part in this study. The answers you give in this questionnaire will help us to find out if the treatments you receive are helpful for your condition.

The information you provide will be completely confidential and will not affect your treatment in any way.

Please answer all the questions. Although it may seem that some questions are asked more than once, it is still important that you answer every one. If you find it difficult to answer a question, please do the best you can.

Please follow the instructions for each section of the questionnaire carefully.

For each section, if you are asked to put a cross in the box, please use a cross, as if you were filling out a ballot paper, rather than a tick.

For example in the following question, if your answer is yes, you should place a cross firmly in the corresponding box.

	Yes	No
Do you drive a car?	☒	☐

Please use a black or blue pen. Do not use a pencil or any other coloured pen.

Please complete the questionnaire fully and return it in the FREEPOST envelope provided as soon as possible. Please do not wait until your appointment to complete it.

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What test are you having? (please write in the box below)

If you are not sure what test you are having, please cross this box. ☐

Are you happy to take part in a telephone interview with one of our researchers?

Yes ☐ No ☐

Please enter your date of birth below

D D / M M / Y Y Y Y

Please enter your sex below

Male ☐ Female ☐

Please enter your initials in the box below

Medication for Colitis	Each tablet dose in mg	Number of tablets per day	Regular?	If not regularly, average number of tablets taken per month
Asacol or Pentasa or Salofalk (Mesalazine)			Yes ☐ No ☐	
Colazide (Balsalazide)			Yes ☐ No ☐	
Dipentum (Olsalazine)			Yes ☐ No ☐	
Salazopyrin (Sulfasalazine)			Yes ☐ No ☐	
Entocort or Budenofalk(Budesonide)			Yes ☐ No ☐	
Prednisolone (by mouth)			Yes ☐ No ☐	

	Number per day	Regular?	If not regularly, average number per month
Predsol or Predfoam or Predenema (enemas)		Yes ☐ No ☐	

If you take any other tablets/liquids for your **digestive or bowel symptoms**, that are not listed, please write the details in the list below. Please include any prescriptions and medicines you buy over the counter from the chemist or supermarket (examples include antacids and laxatives)

Name of medicine	On prescription	Dose in mg or ml	How many times taken per week
	Yes ☐ No ☐		
	Yes ☐ No ☐		
	Yes ☐ No ☐		
	Yes ☐ No ☐		
	Yes ☐ No ☐		
	Yes ☐ No ☐		

If you wish to add any comments regarding your medication, please enter them in the box below.

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Evaluating Innovations in Gastroenterology for the NHS Modernisation Agency (ENIGMA)

Consent

	Please cross each box to show that you agree with the statement
I have received the patient information sheet, understand the study and agree to participate.	☐
I understand that I will be asked to complete questions about my health, feelings and quality of life and views about the service.	☐
I understand that my participation is voluntary and that I can withdraw from the study at any time, and this will not affect my medical care.	☐
I understand that my General Practitioner will be notified of my participation in this study, unless I request that this does not happen.	☐
I understand that the study team may look at my medical notes. I give permission for the study team to access my medical notes for the purposes of this research.	☐

Signature _____ Date _____

Name in capitals _____

Please complete your name and address so that we can send you the second questionnaire and the name and address of your GP so that we can notify him/her of your inclusion in the study.

Name & address	GP Name & address
.....	.....
.....	.....
.....	.....
.....	.....
Postcode	Postcode .....

Please sign below if you **do not** want your General Practitioner to be notified.

I do not wish my General Practitioner to be notified that I am taking part in this study.

Signature _____ Date _____

SECTION E

Look at the list of medications below. If you take any of the medications listed below, please enter the dose of each tablet (this will be written on the tablet box or bottle) and the number of tablets you take each day. Answer 'yes' or 'no' to whether you are taking the drug regularly and if you answer 'no' please enter the average number of tablets you take each month.

	Each tablet dose in mg	Number of tablets per day	Regular?		If not regularly, average number of tablets taken per month
Indigestion medication					
Nexium (Esomeprazole)			Yes ☐	No ☐	
Losec (Omeprazole)			Yes ☐	No ☐	
Zoton (Lansoprazole)			Yes ☐	No ☐	
Protium (Pantoprazole)			Yes ☐	No ☐	
Pariet (Rabeprazole)			Yes ☐	No ☐	
Zantac (Ranitidine)			Yes ☐	No ☐	
Pepcid (Famotidine)			Yes ☐	No ☐	
Axid (Nizatidine)			Yes ☐	No ☐	
Tagamet (Cimetidine)			Yes ☐	No ☐	
Maxolon (Metoclopramide)			Yes ☐	No ☐	
Motilium (Domperidone)			Yes ☐	No ☐	
Medication for irritable bowel					
Spasmonal (Alverine)			Yes ☐	No ☐	
Merbentyl (Dicycloverine)			Yes ☐	No ☐	
Buscopan (Hyoscine)			Yes ☐	No ☐	
Colpermin			Yes ☐	No ☐	
Colofac (Mebeverine)			Yes ☐	No ☐	
Fybogel			Yes ☐	No ☐	
Anti-diarrhoeal medication					
Imodium (Loperamide)			Yes ☐	No ☐	
Codeine Phosphate			Yes ☐	No ☐	
Questran (Colestyramine)			Yes ☐	No ☐	
Lomotil (Co-phenetrope)			Yes ☐	No ☐	

D5. How many times have you been seen, for any reason at a hospital outpatient clinic in the **last 3 months**?

By a Doctor ☐☐ If none enter '0'

By a Nurse Practitioner ☐☐ If none enter '0'

By a Dietician ☐☐ If none enter '0'

By anyone else (please specify) _____ ☐☐ If none enter '0'

D6. How many times have you been admitted as a day case for upper or lower endoscopy in the **last 3 months**?

Upper endoscopy ☐☐ If none enter '0'

Lower endoscopy ☐☐ If none enter '0'

D7. If you are in work, how many days work have you lost due to illness or in order to see any health professional in the **last 3 months**?

☐☐ If none enter '0'

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☐☐☐☐☐

Please enter the date you are completing this questionnaire below

☐☐ / ☐☐ / ☐☐☐☐
D D M M Y Y Y Y

SECTION A

This section asks about your symptoms. When answering the questions about the effect on your life, consider how these symptoms prevented you from doing your usual activities over the **last 2 weeks**.

Answer each question by **putting a cross in the corresponding box**. Do not cross more than one box in each group. If you are unsure about how to answer a question, please give the best answer you can.

A1. In the **last 2 weeks**, how often have you experienced heartburn (a burning sensation behind your breast bone)?

Not at all ☐
Once a week ☐
Two or three times a week ☐
Most days ☐
Everyday ☐

A2. In the **last 2 weeks**, how often have you had any discomfort in your upper abdomen (above your belly button and below your ribs)?

Not at all ☐
Once a week ☐
Two or three times a week ☐
Most days ☐
Everyday ☐

If you have **not** had any of the symptoms or problems described in questions A1 and A2, skip question A3 and go straight to question A4 over the page

A3. In the **last 2 weeks**, how much have the symptoms described in questions A1 and A2 prevented you from doing your usual activities?

Not at all ☐
A little ☐
Moderately ☐
A lot ☐
Extremely ☐

A4. In the **last 2 weeks**, how often have you experienced bitter bile or acid reflux (from the stomach into the throat)?

Not at all ☐
Once a week ☐
Two or three times a week ☐
Most days ☐
Everyday ☐

A5. In the **last 2 weeks**, how often have you experienced a feeling of nausea or sickness without actually vomiting?

Not at all ☐
Once a week ☐
Two or three times a week ☐
Most days ☐
Everyday ☐

A6. In the **last 2 weeks**, how often have you retched or heaved without actually vomiting?

Not at all ☐
Once a week ☐
Two or three times a week ☐
Most days ☐
Everyday ☐

A7. In the **last 2 weeks**, how often have you actually vomited?

Not at all ☐
Once a week ☐
Two or three times a week ☐
Most days ☐
Everyday ☐

SECTION D

This section is about the health care you have had in the **last 3 months**. Please read each question carefully. For each question, if you have had no treatment or visits enter '0' as indicated.

We would like to know about visits to health professionals **for any reason**, not just your digestive or bowel symptoms.

D1. How often have you consulted, for any reason, any of the following at your GP's surgery in the **last 3 months**?

Your own or another GP ☐☐ If none enter '0'

Nurse ☐☐ If none enter '0'

Other (please specify) _____ ☐☐ If none enter '0'

D2. How often have you consulted, for any reason, any of the following at home in the **last 3 months**?

Your own or another GP ☐☐ If none enter '0'

Nurse ☐☐ If none enter '0'

Other (please specify) _____ ☐☐ If none enter '0'

D3. How often have you been admitted, for any reason, to a hospital (NHS or private) as an emergency in the **last 3 months**?

☐☐ If none enter '0'

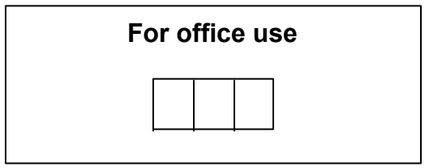
D4. How often have you been admitted, for any reason, to a hospital (NHS or private) NOT as an emergency in the **last 3 months**?

☐☐ If none enter '0'

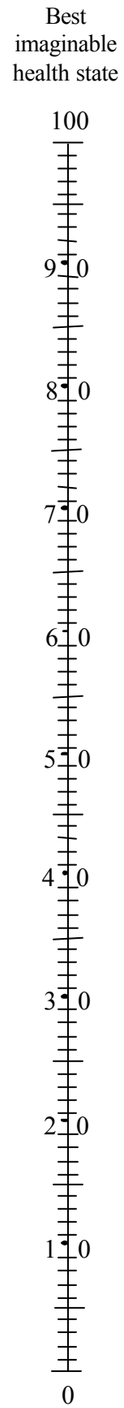
To help people say how good or bad their health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the black box below to whichever point on the scale indicates how good or bad **your health state is today.**

For office use



Your own health state today



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A8. If you have vomited in the **last 2 weeks**, have you seen any blood in the vomit?

- Yes ☐
- No ☐
- Not applicable ☐

If you have **not** had any of the symptoms or problems described in questions A4 to A8, skip question A9 and go directly to question A10

A9. In the **last 2 weeks**, how much have the symptoms described in question A4 to question A8 prevented you from doing your usual activities?

- Not at all ☐
- A little ☐
- Moderately ☐
- A lot ☐
- Extremely ☐

A10. In the **last 2 weeks**, how often have you been bothered by a lot of belching or burping (release of wind from the stomach by the mouth)?

- Not at all ☐
- Once a week ☐
- Two or three times a week ☐
- Most days ☐
- Everyday ☐

A11. In the **last 2 weeks**, how often have you been bothered by passing a lot of wind from the back passage?

- Not at all ☐
- Once a week ☐
- Two or three times a week ☐
- Most days ☐
- Everyday ☐

A12. In the **last 2 weeks**, how often have you experienced bloatedness, and or a feeling of trapped wind in your stomach?

- Not at all ☐
- Once a week ☐
- Two or three times a week ☐
- Most days ☐
- Everyday ☐

A13. In the **last 2 weeks**, how often have you experienced loud gurgling noises from your stomach?

- Not at all ☐
- Once a week ☐
- Two or three times a week ☐
- Most days ☐
- Everyday ☐

If you have **not** had any of the symptoms or problems described in questions A10 to A13, skip question A14 and go straight to question A15 over the page

A14. In the **last 2 weeks**, how much have the symptoms described in question A10 to question A13 prevented you from doing your usual activities?

- Not at all ☐
- A little ☐
- Moderately ☐
- A lot ☐
- Extremely ☐

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SECTION C

This section asks about your health in general. Please indicate which statement best describes **your own health state today**.

Answer each question by **putting a cross in the corresponding box.** Do not cross more than one box in each group. If you are unsure about how to answer a question, please give the best answer you can.

C1. Mobility

- I have no problems in walking about ☐
- I have some problems in walking about ☐
- I am confined to bed ☐

C2. Self care

- I have no problems with self-care ☐
- I have some problems with self-care ☐
- I am unable to wash or dress myself ☐

C3. Usual Activities

- I have no problems with performing my usual activities ☐
- I have some problems with performing my usual activities ☐
- I am unable to perform my usual activities ☐

C4. Pain / Discomfort

- I have no pain or discomfort ☐
- I have moderate pain or discomfort ☐
- I have extreme pain or discomfort ☐

C5. Anxiety/Depression

- I am not anxious or depressed ☐
- I am moderately anxious or depressed ☐
- I am extremely anxious or depressed ☐

B10. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐	☐	☐	☐	☐

B11. How TRUE or FALSE is each of the following statements for you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
I seem to get sick a little easier than other people	☐	☐	☐	☐	☐
I am as healthy as anybody I know	☐	☐	☐	☐	☐
I expect my health to get worse	☐	☐	☐	☐	☐
My health is excellent	☐	☐	☐	☐	☐

A15. In the **last 2 weeks**, how often have you felt that your food sticks on the way down your gullet (through the chest into your stomach)?

- Not at all ☐
- Once a week ☐
- Two or three times a week ☐
- Most days ☐
- Everyday ☐

A16. In the **last 2 weeks**, how often have your eating habits been restricted because of your condition (examples might be having to eat more slowly, having to take smaller portions or having to eat different foods)?

- Not at all ☐
- Once a week ☐
- Two or three times a week ☐
- Most days ☐
- Everyday ☐

A17. In the **last 2 weeks** have you had a lack of appetite?

- Not at all ☐
- Once a week ☐
- Two or three times a week ☐
- Most days ☐
- Everyday ☐

If you have **not** had any of the symptoms or problems described in questions A15 to A17, skip question A18 and go to question A19 over the page

A18. In the **last 2 weeks**, how much have the symptoms described in question A15 to question A17 prevented you from doing your usual activities?

- Not at all ☐
- A little ☐
- Moderately ☐
- A lot ☐
- Extremely ☐

A19. Have you noticed any change in weight (not due to a change in your diet) over the **last 3 months**?

- No, my weight has been stable ☐
- Yes, I have been gaining weight ☐
- Yes, I have been losing weight ☐

A20. In the **last 2 weeks**, how often have you been bothered by too frequent emptying of your bowels?

- Not at all ☐
- Once a week ☐
- Two or three times a week ☐
- Most days ☐
- Everyday ☐

A21. In the **last 2 weeks**, how often have you been bothered by loose stools?

- Not at all ☐
- Once a week ☐
- Two or three times a week ☐
- Most days ☐
- Everyday ☐

A22. In the **last 2 weeks**, how often have you been bothered by hard stools?

- Not at all ☐
- Once a week ☐
- Two or three times a week ☐
- Most days ☐
- Everyday ☐

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B7. How much bodily pain have you had during the **past 4 weeks**?

None	Very mild	Mild	Moderate	Severe	Very severe
☐	☐	☐	☐	☐	☐

B8. During the **past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	Slightly	Moderately	Quite a bit	Extremely
☐	☐	☐	☐	☐

B9. These questions are about how you feel and how things have been with you during the **past 4 weeks**. For each question, please give ONE answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks** .....

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Did you feel full of life?	☐	☐	☐	☐	☐
Have you been very nervous?	☐	☐	☐	☐	☐
Have you felt so down in the dumps that nothing could cheer you up?	☐	☐	☐	☐	☐
Have you felt calm and peaceful?	☐	☐	☐	☐	☐
Did you have a lot of energy?	☐	☐	☐	☐	☐
Have you felt downhearted and depressed?	☐	☐	☐	☐	☐
Did you feel worn out?	☐	☐	☐	☐	☐
Have you been happy?	☐	☐	☐	☐	☐
Did you feel tired?	☐	☐	☐	☐	☐

B4. During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Cut down on the amount of time you spent on work or other activities	☐	☐	☐	☐	☐
Accomplished less than you would like	☐	☐	☐	☐	☐
Were limited in the kind of work or other activities	☐	☐	☐	☐	☐
Had difficulty performing the work or other activities (for example, it took extra effort)	☐	☐	☐	☐	☐

B5. During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Cut down on the amount of time you spent on work or other activities	☐	☐	☐	☐	☐
Accomplished less than you would like	☐	☐	☐	☐	☐
Did work or activities less carefully than usual	☐	☐	☐	☐	☐

B6. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal activities with family, friends, neighbours, or groups?

Not at all	Slightly	Moderately	Quite a bit	Extremely
☐	☐	☐	☐	☐

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A23. In the **last 2 weeks**, how often have you been bothered by constipation (constipation means difficulty in emptying your bowels)?

- Not at all ☐
- Once a week ☐
- Two or three times a week ☐
- Most days ☐
- Everyday ☐

A24. In the **last 2 weeks**, how often have you had an urgent need to empty your bowels (this urgent need is often associated with a feeling that you are not in full control)?

- Not at all ☐
- Once a week ☐
- Two or three times a week ☐
- Most days ☐
- Everyday ☐

A25. In the **last 2 weeks,** how often have you had a feeling of not completely emptying your bowels?

- Not at all ☐
- Once a week ☐
- Two or three times a week ☐
- Most days ☐
- Everyday ☐

A26. In the **last 2 weeks**, have you had bleeding through your back passage (signs of bleeding include fresh blood, staining of toilet tissue, blood mixed with stools)?

- Not at all ☐
- A little ☐
- Moderately ☐
- A lot ☐
- Extremely ☐

If you have **not** had any of the symptoms or problems described in questions A20 to A26, skip question A27 and go straight to question A28

A27. In the **last 2 weeks**, how much have the symptoms described in question A20 to question A26 prevented you from doing your usual activities?

- Not at all ☐
- A little ☐
- Moderately ☐
- A lot ☐
- Extremely ☐

A28. Compared with **2 weeks ago**, how would you now rate your symptoms in general?

- Much better now than 2 weeks ago ☐
- Somewhat better now than 2 weeks ago ☐
- About the same as 2 weeks ago ☐
- Somewhat worse now than 2 weeks ago ☐
- Much worse now than 2 weeks ago ☐

A29. In the **last 2 weeks**, how often have your symptoms caused you difficulties in getting to sleep?

- Not at all ☐
- Once a week ☐
- Two or three times a week ☐
- Most nights ☐
- Every night ☐

A30. In the **last 2 weeks**, how often have your symptoms caused you to wake up?

- Not at all ☐
- Once a week ☐
- Two or three times a week ☐
- Most nights ☐
- Every night ☐

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SECTION B

This section asks for your views about your health, how you feel and how well you are able to do your usual activities.

Answer every question by **putting a cross in the corresponding box**. Do not cross more than one box in each group. If you are unsure about how to answer a question, please give the best answer you can.

B1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
☐	☐	☐	☐	☐

B2. Compared to **1 year ago**, how would you rate your health in general now?

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
☐	☐	☐	☐	☐

B3. The following questions are about activities you might do during **a typical day**. Does your health now limit you in these activities? If so, how much? (**cross a box on each line**)

	Yes, limited a lot	Yes, limited a little	No, not limited at all
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	☐	☐	☐
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf	☐	☐	☐
Lifting or carrying groceries	☐	☐	☐
Climbing several flights of stairs	☐	☐	☐
Climbing one flight of stairs	☐	☐	☐
Bending, kneeling or stooping	☐	☐	☐
Walking more than a mile	☐	☐	☐
Walking several hundred yards	☐	☐	☐
Walking one hundred yards	☐	☐	☐
Bathing or dressing yourself	☐	☐	☐