

IBD Benchmarking Tool 2019/2020
Patient Survey Report

Edinburgh Royal Hospital for Sick Children

Working together for everyone affected by Inflammatory Bowel Disease

www.ibduk.org

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Acknowledgements

Foreword

I am delighted to be able to share with you the results from the Inflammatory Bowel Disease (IBD) Patient Survey 2019 for Edinburgh Royal Hospital for Sick Children, available online at www.ibduk.org

This is the first time that patients have had the opportunity to feedback on the quality of care they receive against the IBD Standards. The IBD Standards were published in 2019 by IBD UK, a partnership of 17 patient and professional organisations working together for everyone affected by IBD. The survey asked people with Crohn's or Colitis a range of questions about their experience of care and the answers have highlighted what local hospitals are doing well, and what they could do better.

It is also the first time that IBD teams have been able to complete a service self-assessment against the IBD Standards, using the IBD Benchmarking Tool. Teams that have completed this assessment have been provided with detailed information on how their assessment compares with their patient survey results. An overview of this comprehensive report is also published on the IBD UK website.

This is only the beginning. Now it's time to take these results and make improvements to care. IBD UK will support hospitals with good practice in quality improvement to ensure that the patient voice is heard throughout. We'll be running a structured programme of workshops and producing a quality improvement toolkit, with templates, case studies and podcasts to help with this process.

The IBD Patient Survey will open again in 2021 and run every two years thereafter, so join us on the journey - together, we can make a real difference.



Rukshana Kapasi
Chair, IBD UK



About this report

This report follows the IBD Standards sections and the patient journey from first symptoms to diagnosis, treatment and ongoing care, as well as how the IBD service should be organised. Each section includes a link to further information, including details on the relevant IBD Standards.

Bar charts in this report show the responses from 34 paediatric patients with Crohn's or Colitis using Edinburgh Royal Hospital for Sick Children and how this compares with paediatric responses from patients across Scotland, as well as the UK. Numbers of respondents are shown for each chart. The numbers of respondents will vary from question to question as not all questions were relevant for all respondents - for example, only those who have been diagnosed within the last two years were asked questions about their diagnosis. Additionally, it was possible to select multiple answers for some questions, so the number of responses may be greater than the number of unique patients. Please note that where there are less than five patients responding, no result will be shown.

The IBD Patient Survey was mostly completed online, between 8th July and 22nd November 2019, with hard copies and translations available, and was promoted through patient organisations and by hospital IBD teams. The total number of respondents across the UK was 10,224, of which 465 were paediatric patients. Of these paediatric patients, 60 were from Scotland.

If your hospital completed a self-assessment, a Results Overview report containing selected data from this self-assessment and the IBD Patient Survey will be available from the IBD UK website. Feedback on the reports is welcomed and can be sent to info@ibduk.org

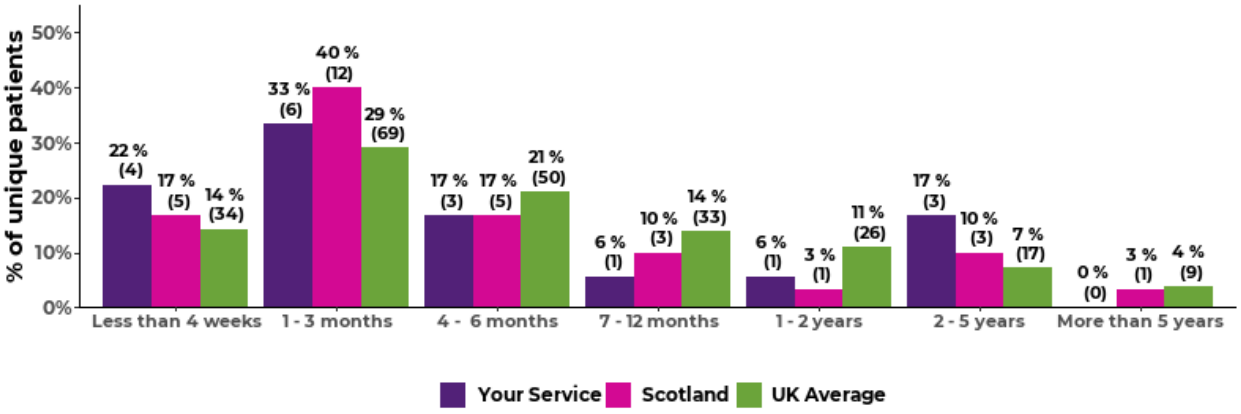
1. Pre-diagnosis

Everyone with IBD should receive an early and accurate diagnosis of their condition. This will mean they get the treatment and support they need sooner and be better able to manage their condition.

More information can be found on this web page www.ibduk.org/ibd-standards/pre-diagnosis

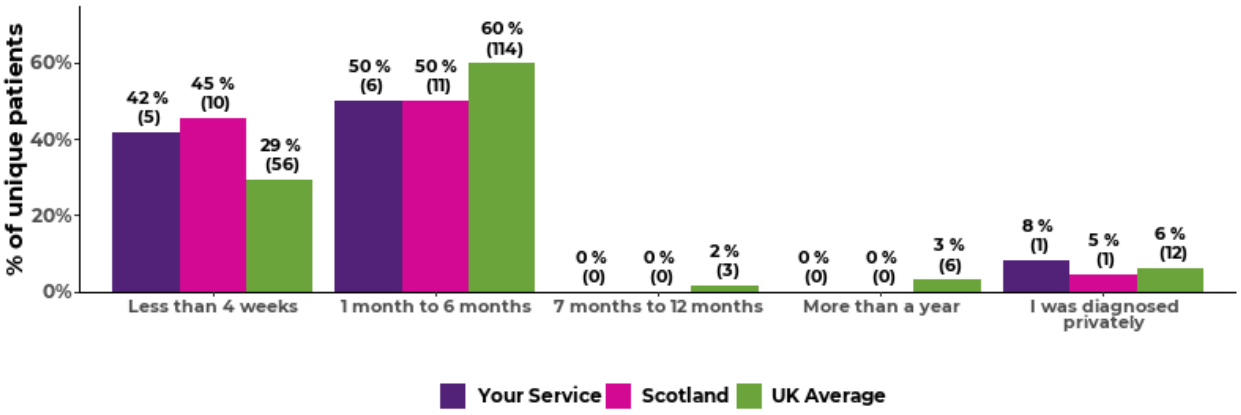
Responses included in this section are from 18 patients who have been diagnosed with IBD within the last 2 years.

1.1 How long did it take from the time you first spoke to a healthcare professional about your symptoms to the time your diagnosis was confirmed?



Patients = 18

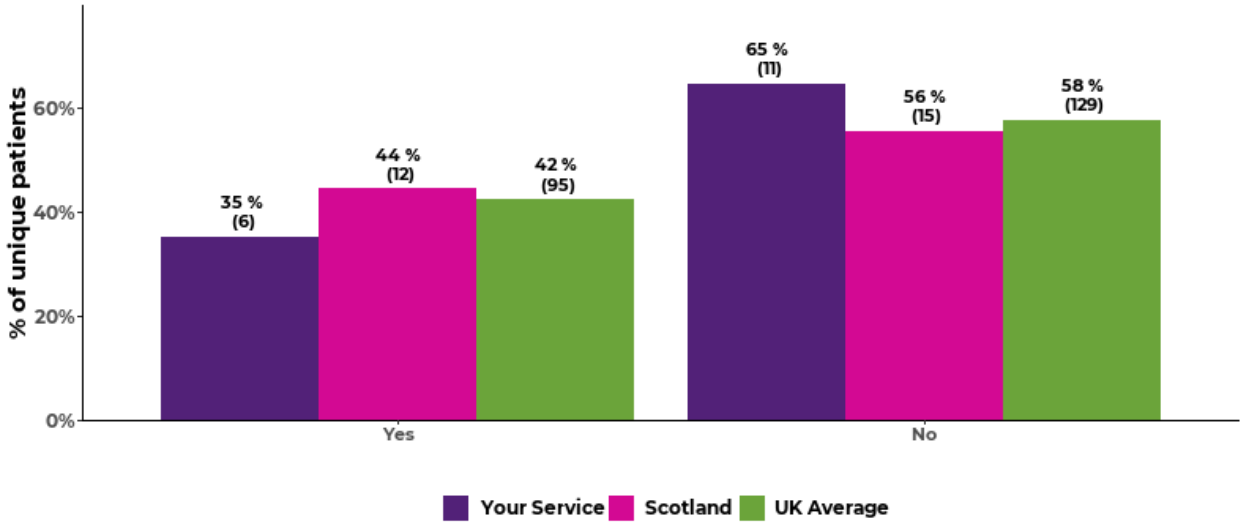
1.2 If a GP referred you to a hospital specialist, how long did you wait for your first appointment?



Patients = 12

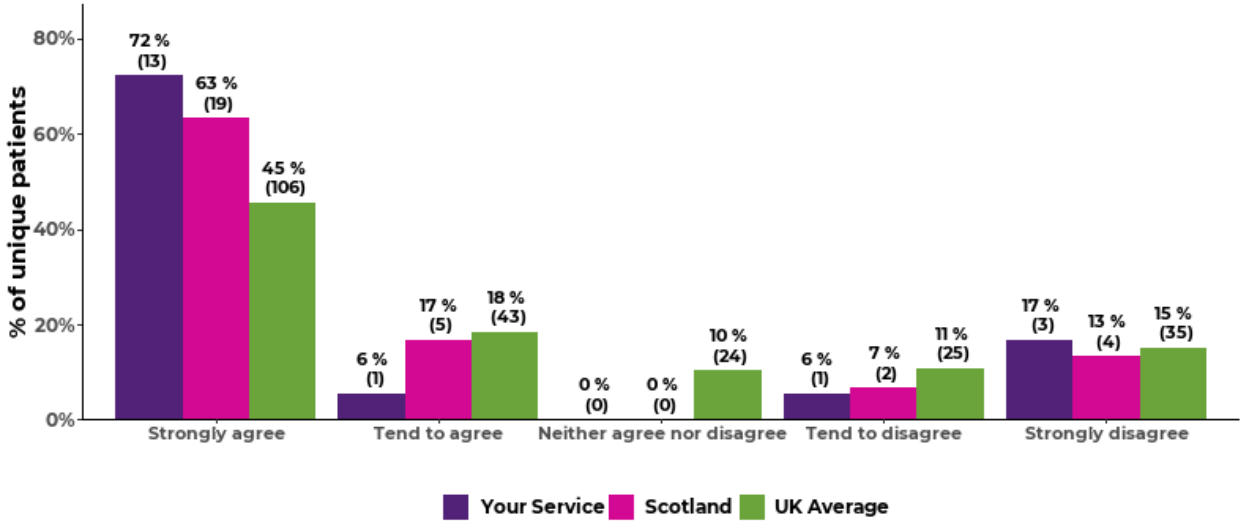
1.3 Before your diagnosis, did your GP offer you a faecal calprotectin or faecal immunochemical test (FIT) before you were referred to hospital for further investigations?

A faecal calprotectin is a stool test that measures the level of active inflammation in the intestine. A FIT test determines the presence of human haemoglobin in the stool. Both are useful indicators of the likelihood of a diagnosis of Crohn's or Colitis.



Patients = 17

1.4 While waiting for my diagnosis to be confirmed, I was given clear information about what was going to happen next and who to contact if I had any questions.



Patients = 18

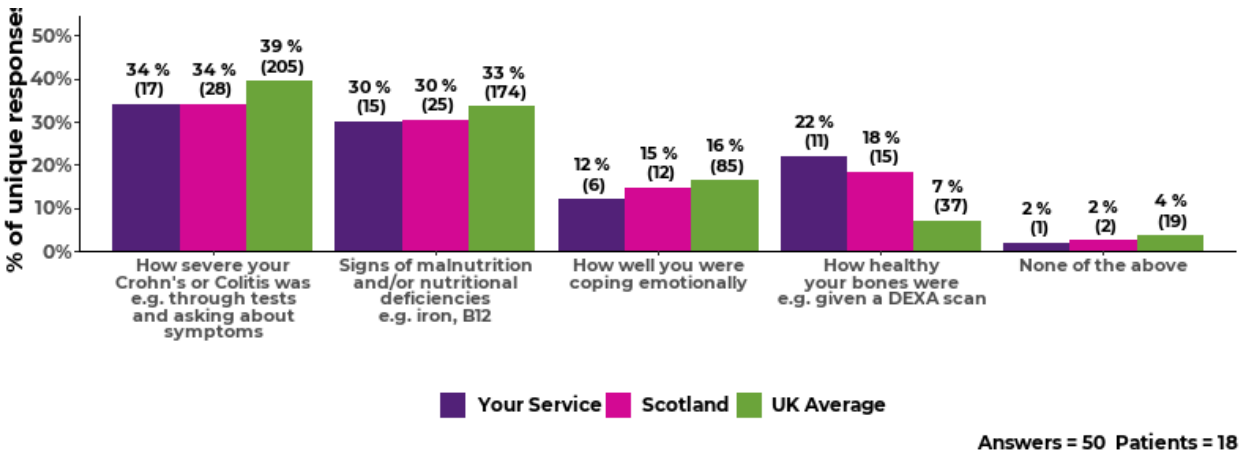
2. Newly diagnosed

It's essential to get the right treatment and support in place for newly diagnosed patients with IBD. This will give them the best outcomes and help them adjust to living with the condition.

More information can be found on this web page www.ibduk.org/ibd-standards/newly-diagnosed

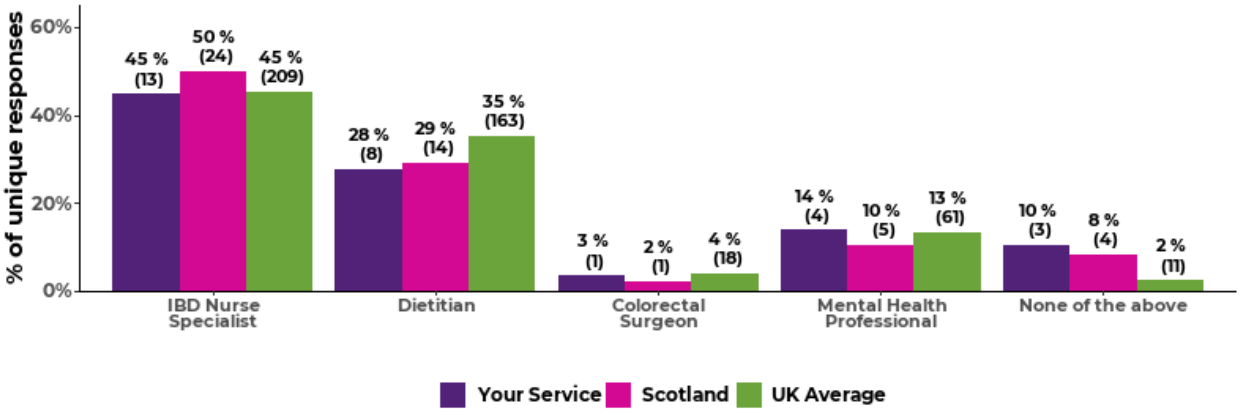
Responses included in this section are from 18 patients who have been diagnosed with IBD within the last 2 years.

2.1 Following your assessment, were you assessed for any of the following?



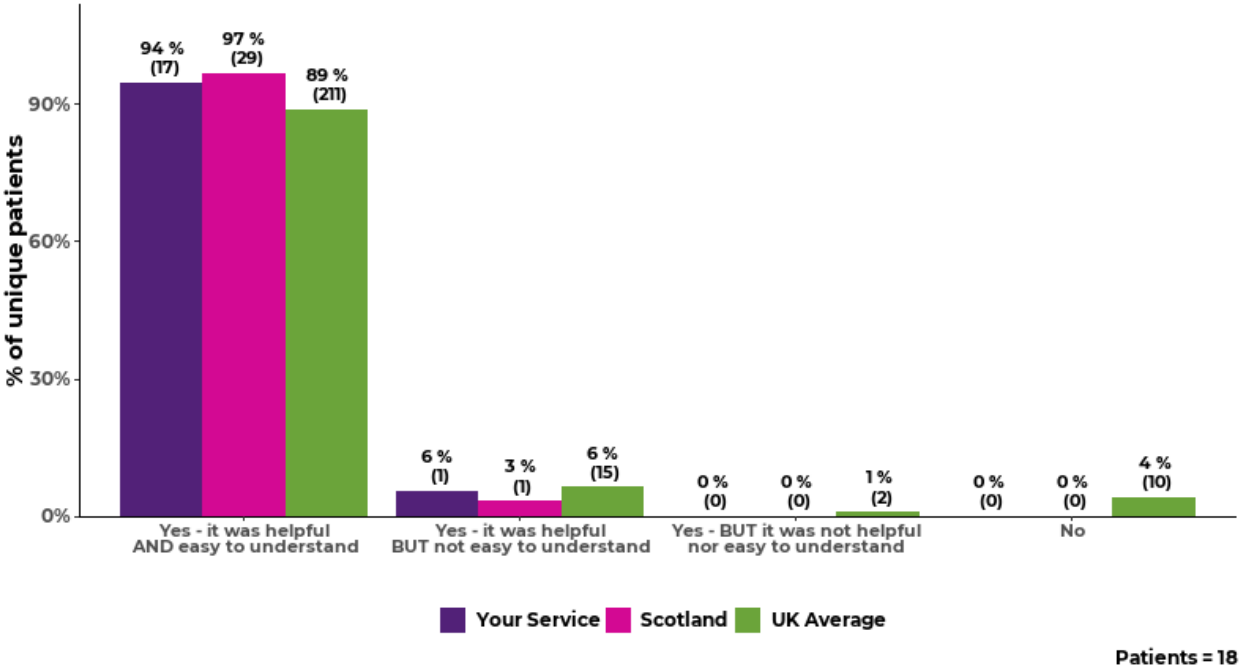
Answers = 50 Patients = 18

2.2 Following your assessment, were you offered the opportunity to be referred to any of the following?



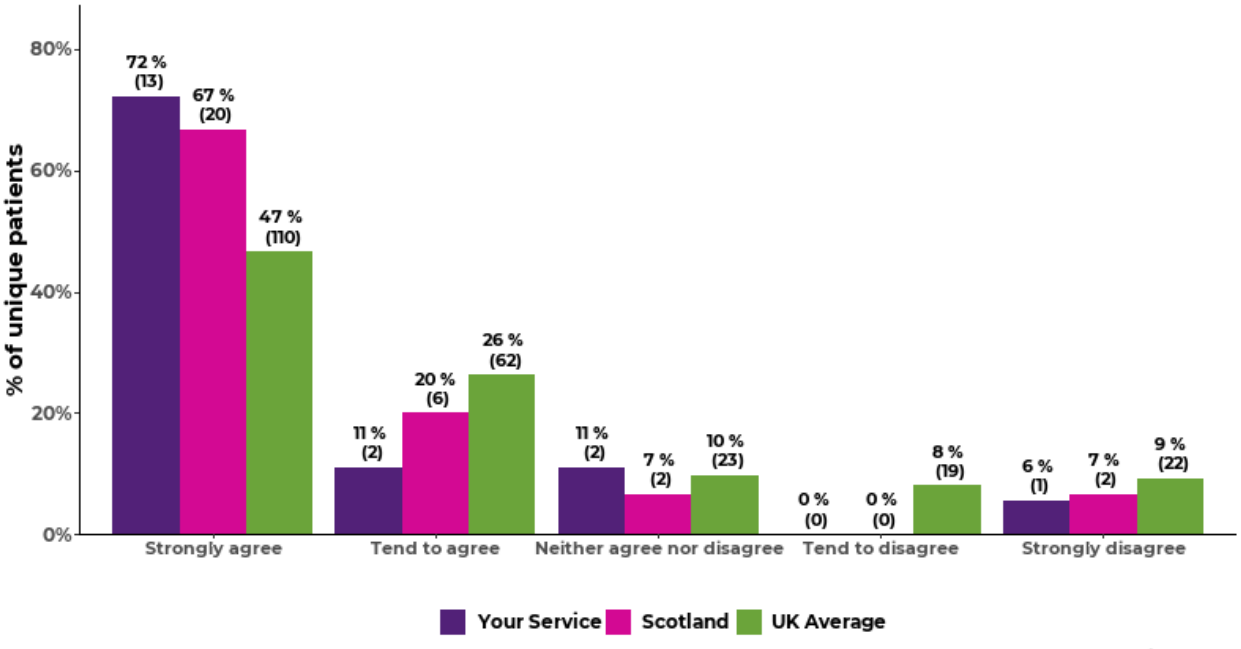
Answers = 29 Patients = 17

2.3 When you were told you had Crohn's or Colitis, were you offered any written information about your condition?



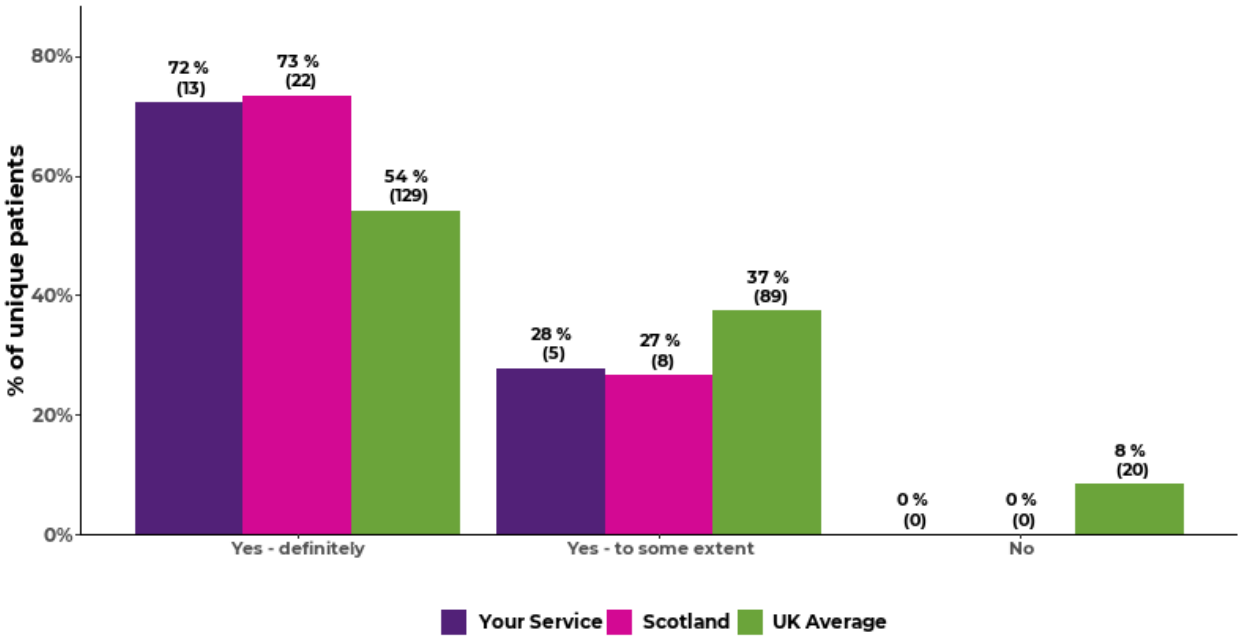
Patients = 18

2.4 I was given enough information about potential treatments and care, including benefits and possible side-effects, to understand the options available to me and make an informed choice.



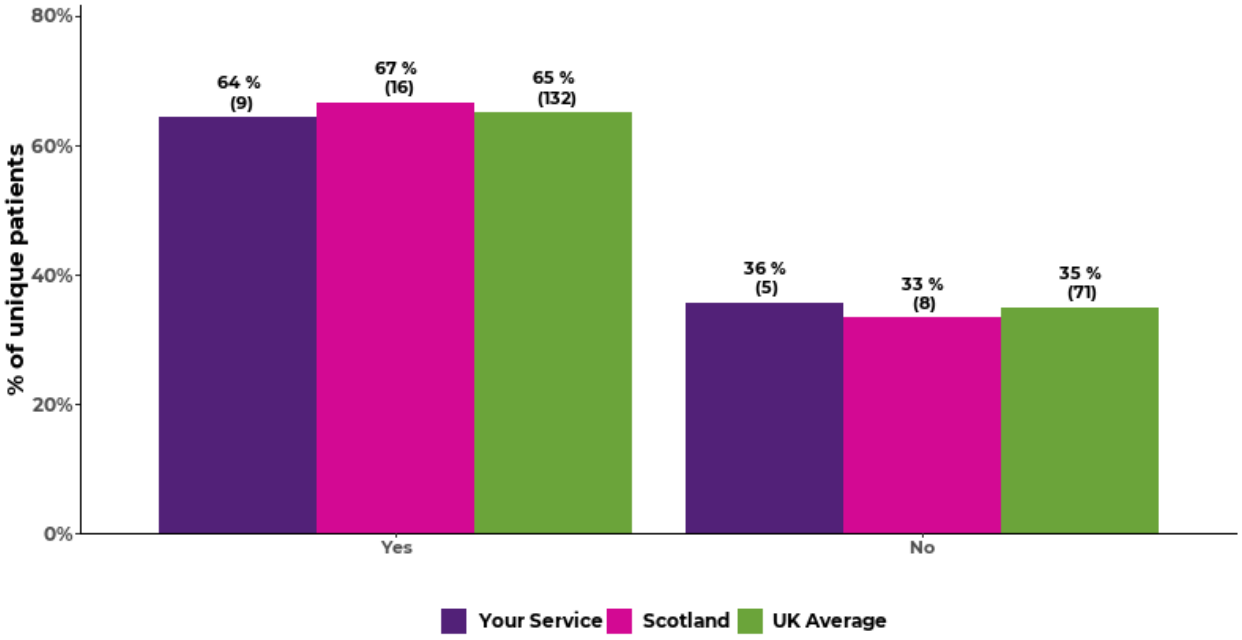
Patients = 18

2.5 Were you involved as much as you wanted to be in decisions about your care and treatment?



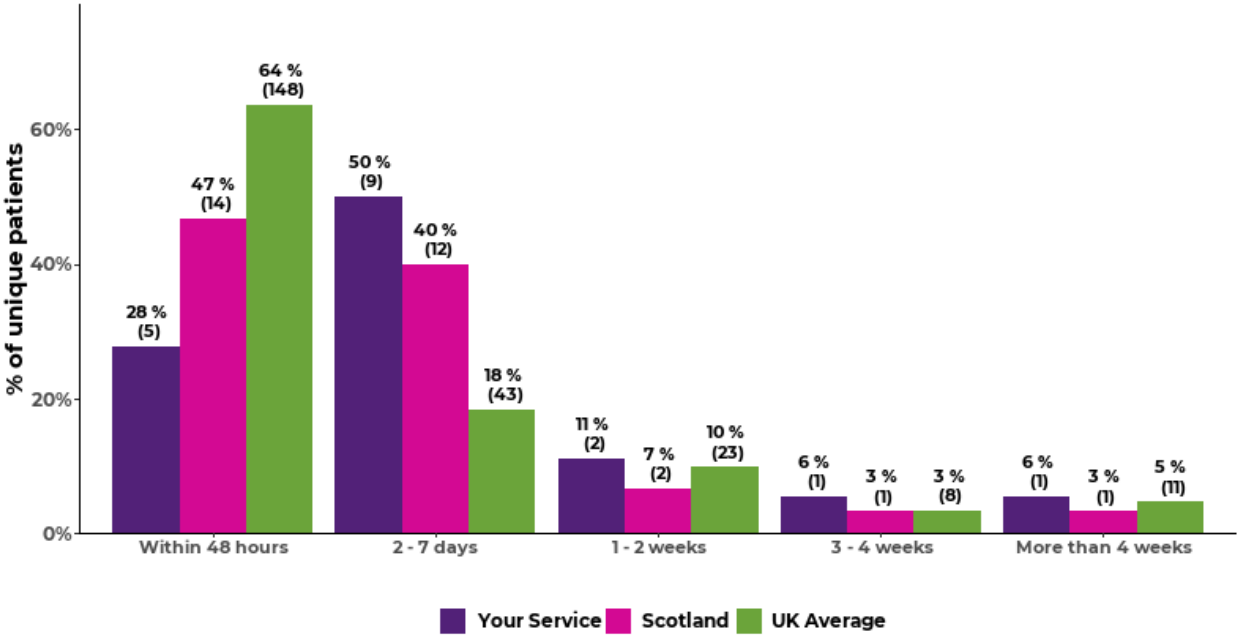
Patients = 18

2.6 Did you have a written first treatment plan?



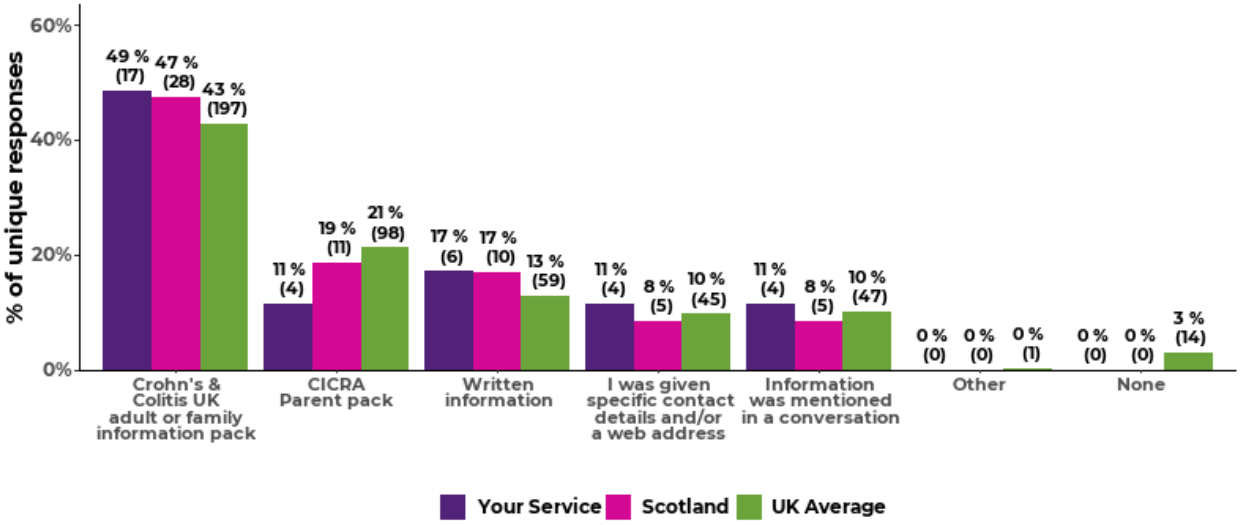
Patients = 14

2.7 How long after your diagnosis were you able to start treatment?



Patients = 18

2.8 When you were told you had Crohn's or Colitis, did a healthcare professional give you any information about relevant patient organisations or charities?



Answers = 35 Patients = 18

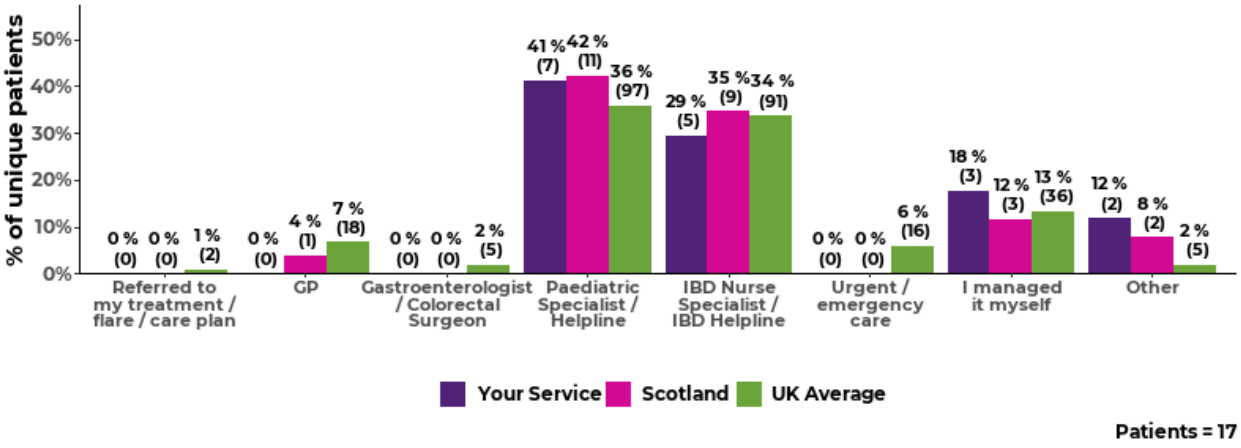
3. Flare management

When people with IBD experience a flare, they must be able recognise it – and access the right specialist advice and treatment to manage it as quickly as possible.

More information can be found on this web page www.ibduk.org/ibd-standards/flare-management

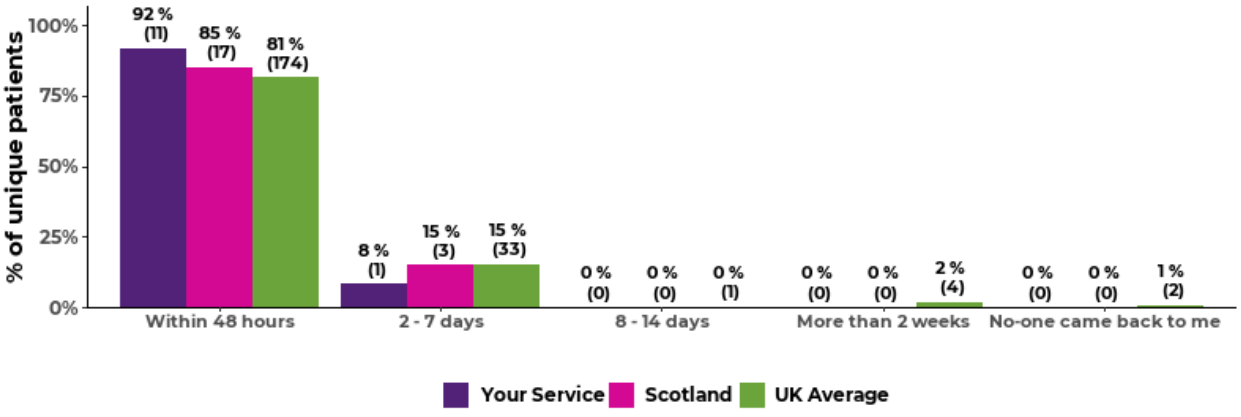
Responses included in this section are from 18 patients who had one or more flares in the last 12 months.

3.1 Thinking about your most recent flare, who did you contact in the first instance?



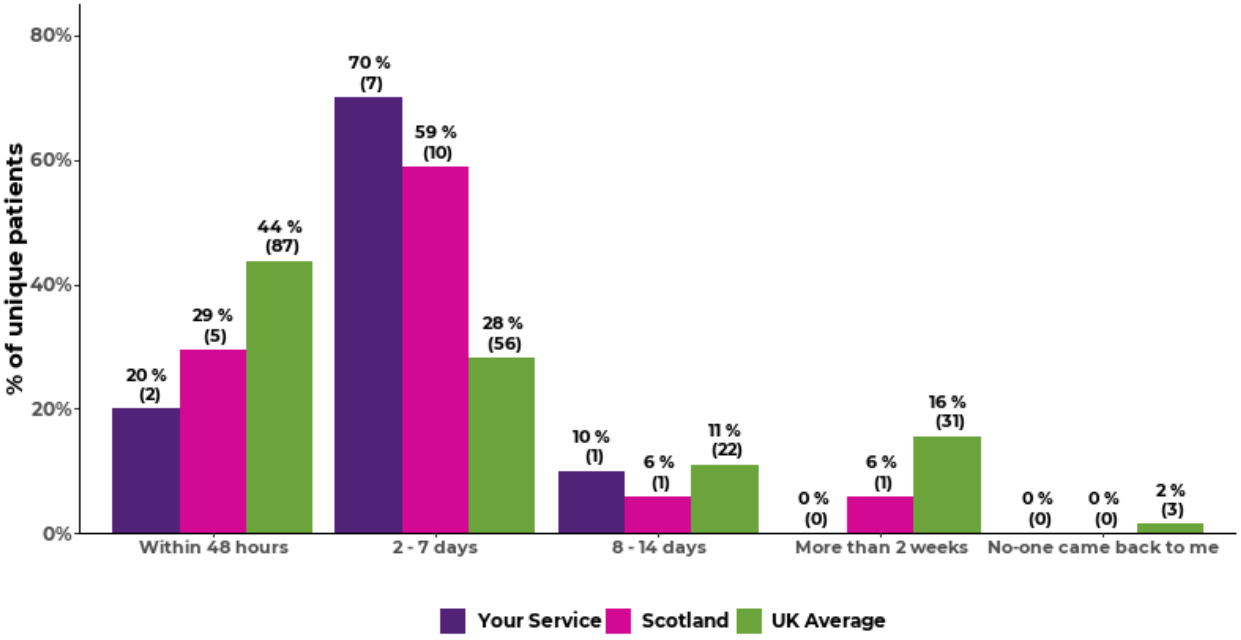
Patients = 17

3.2 How long was it before you received a response?



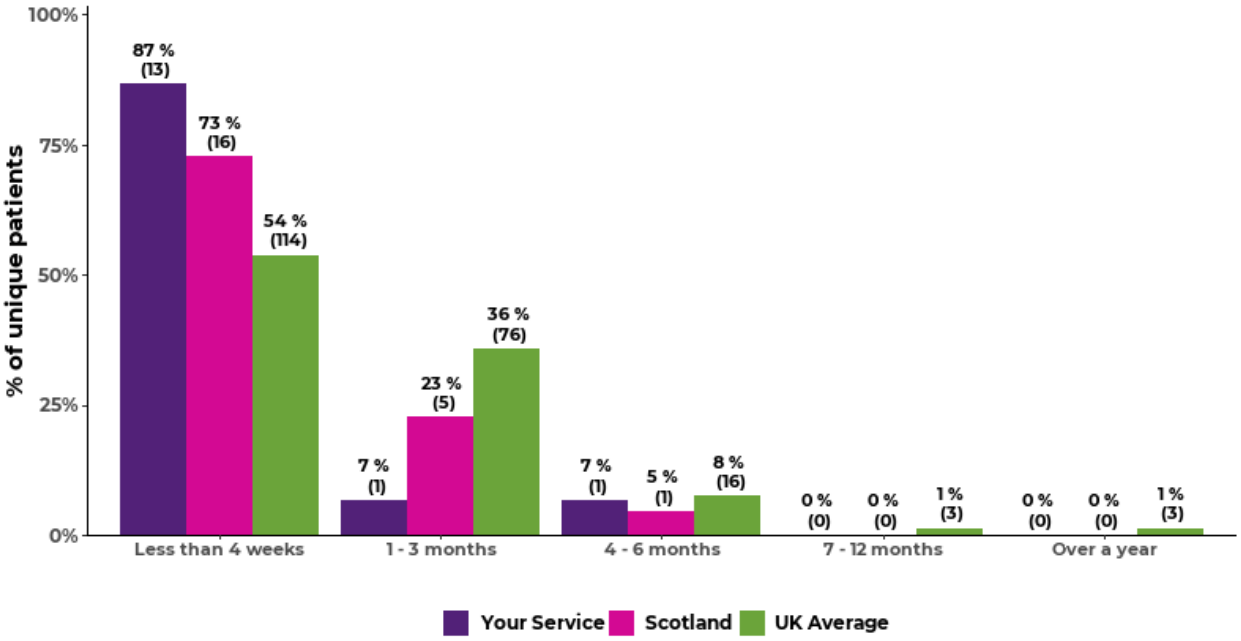
Patients = 12

3.3 How long after were you able to start treatment?



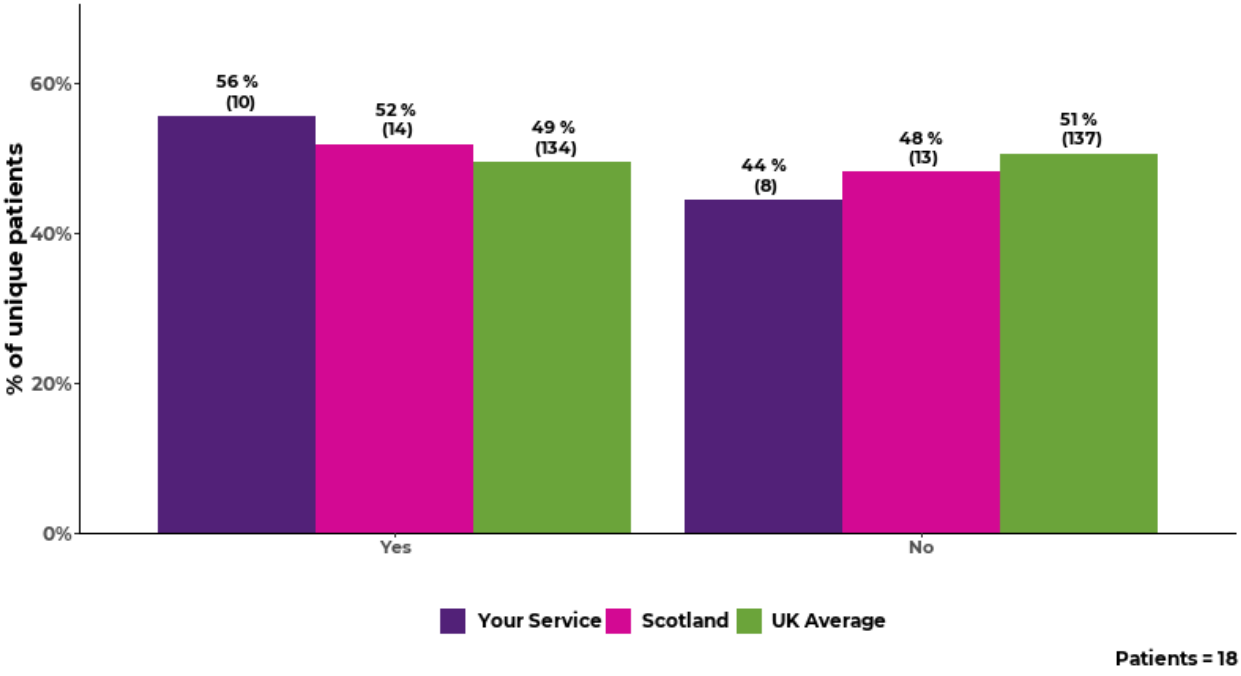
Patients = 10

3.4 If you had an investigative test in the last 12 months, on average how long did you wait?



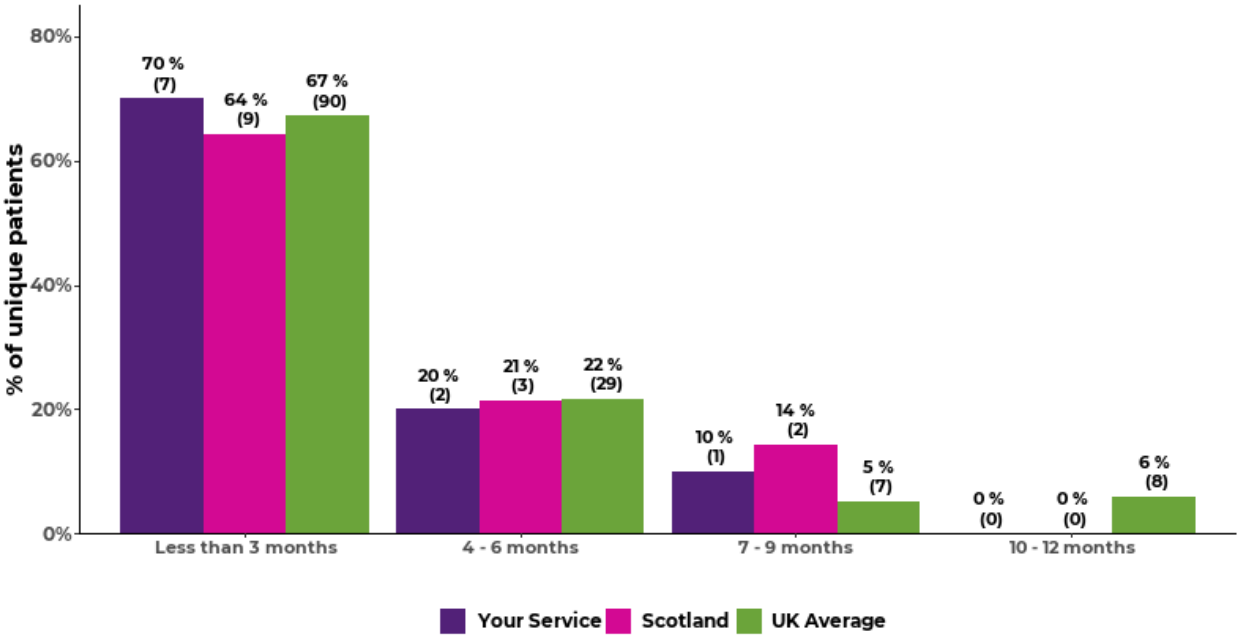
Patients = 15

3.5 Have you taken steroid tablets for your Crohn's or Colitis at any time in the last 12 months?



Patients = 18

3.6 What is the longest continuous stretch of time that you have taken a course of steroid tablets within the last 12 months?



Patients = 10

4. Surgery and inpatient care

Patient outcomes are better when IBD surgery is timely, led by surgeons with the right expertise, and with effective multidisciplinary working. It's important that patients fully understand their options and are offered psychological support.

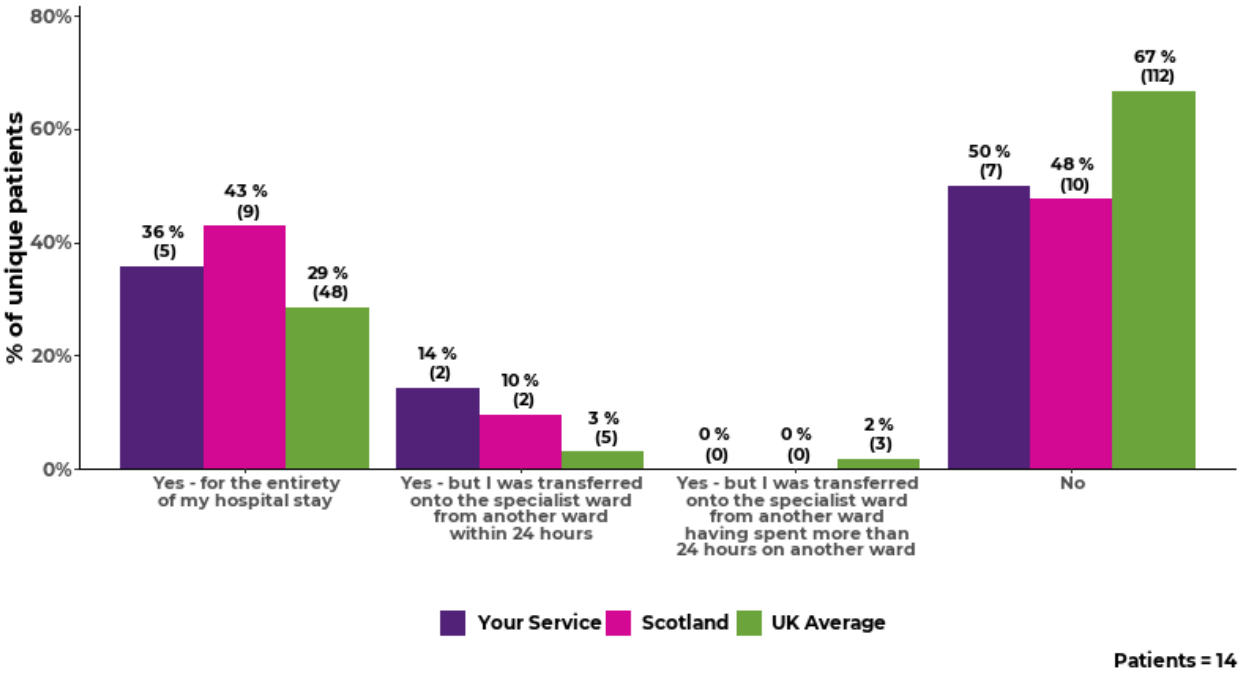
More information can be found on this web page www.ibduk.org/ibd-standards/surgery

For the best outcomes and experience, inpatients with IBD should be admitted to a specialist ward with appropriate facilities and specialist review. They should receive a holistic assessment and be offered appropriate services and support as a result. On discharge, they should have clear information and coordination of care.

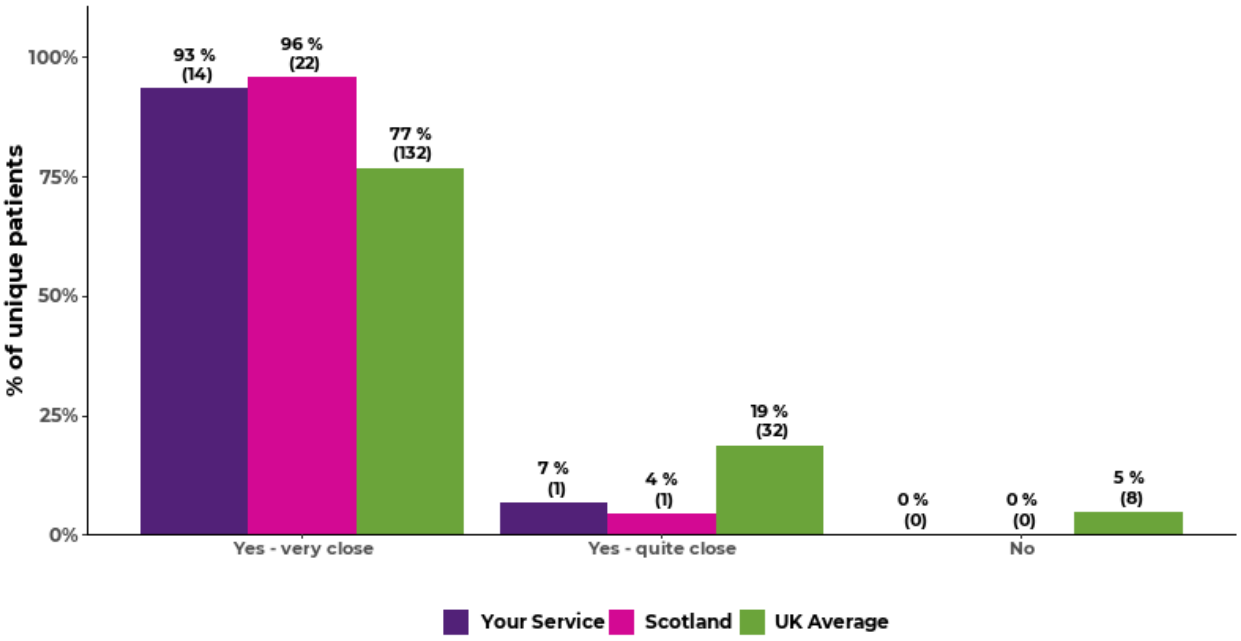
More information can be found on this web page www.ibduk.org/ibd-standards/inpatient-care

Responses included in this section are from 15 patients who have been admitted to hospital because of Crohn's or Colitis-related symptoms in the last 12 months.

4.1 Did you stay on a ward that cared mainly for patients with bowel conditions, also known as a 'gastroenterology' ward?

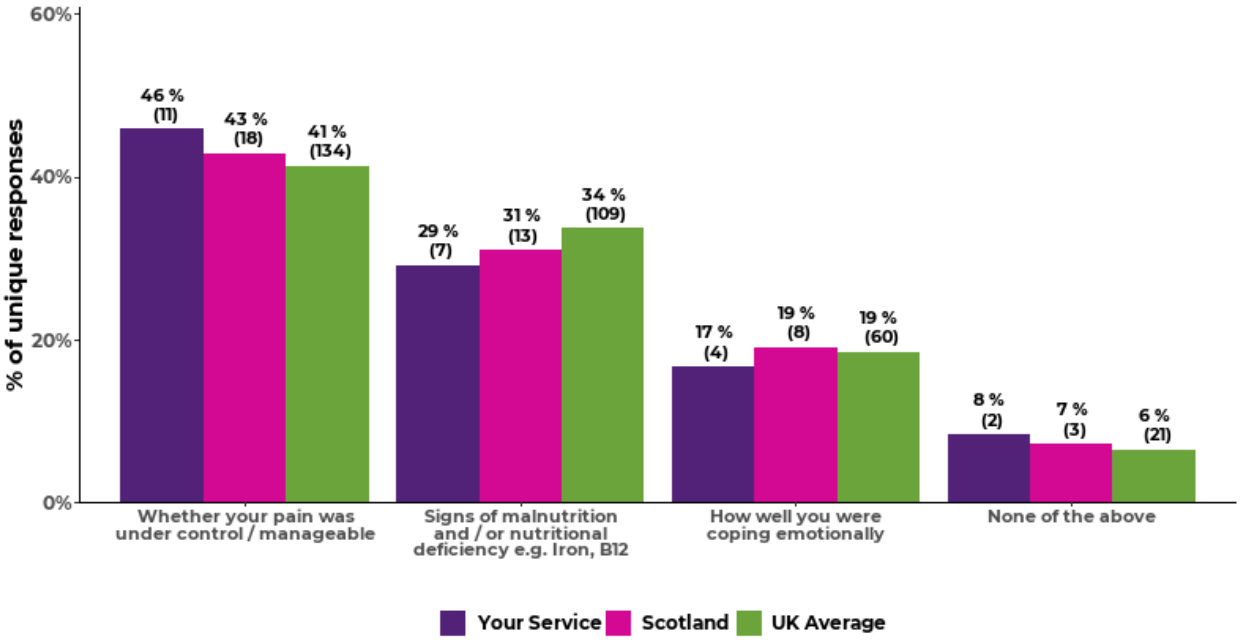


4.2 When you needed to use a toilet or bathroom, was a suitable one located close by on your ward?



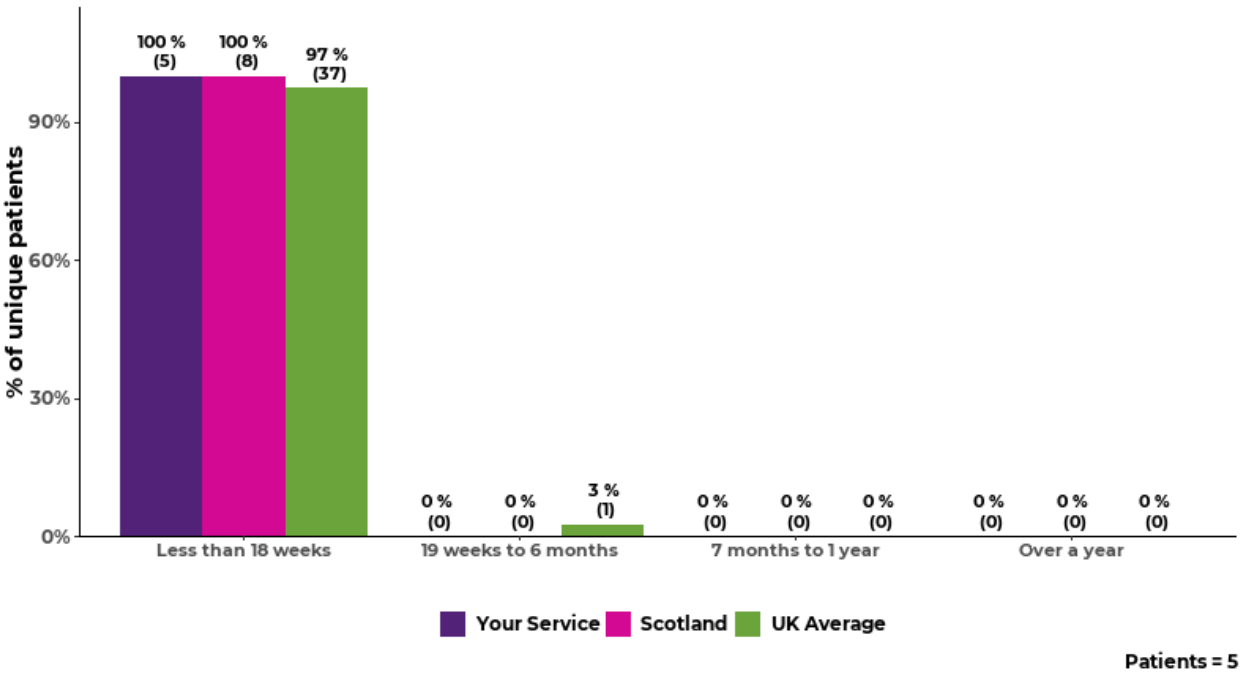
Patients = 15

4.3 When admitted to hospital, were you assessed for any of the following?



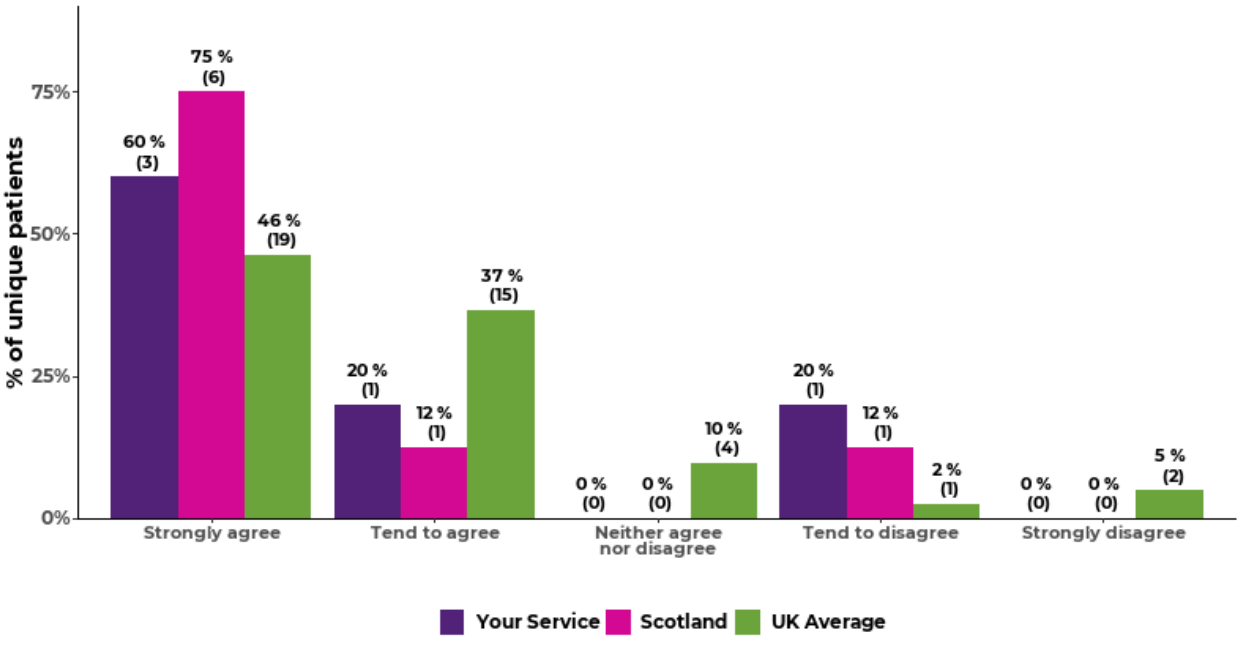
Answers = 24 Patients = 15

4.4 If you were referred for an operation, how long did you wait?



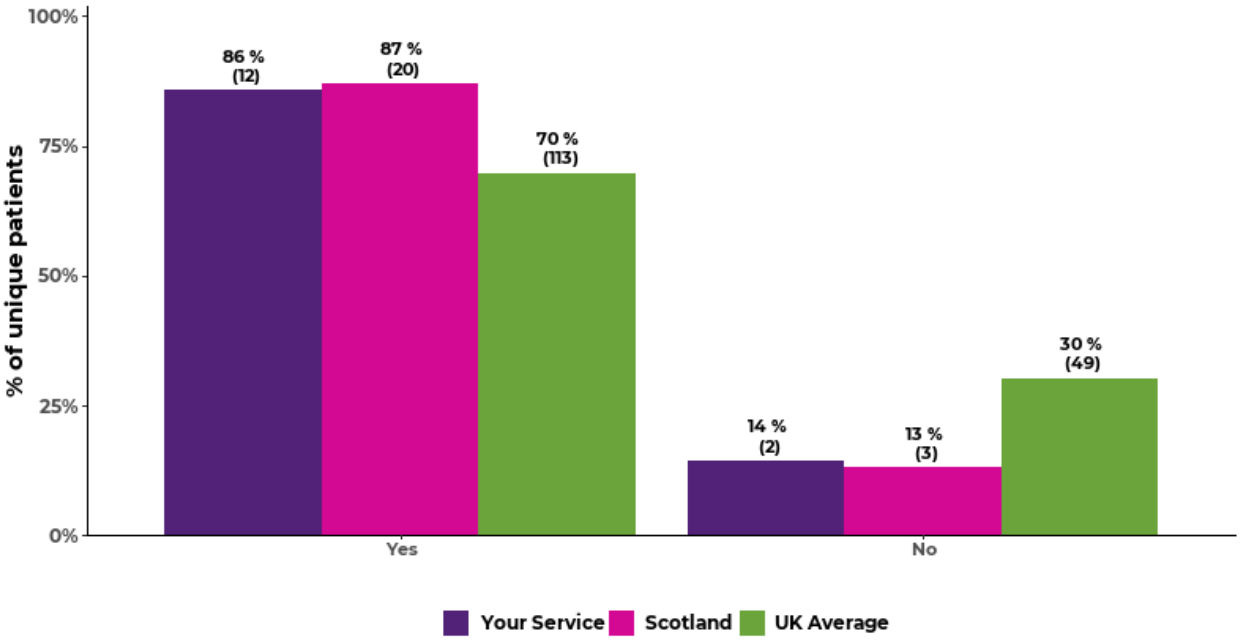
Patients = 5

4.5 I was given information in a format that helped me understand the benefits and risks of surgery.



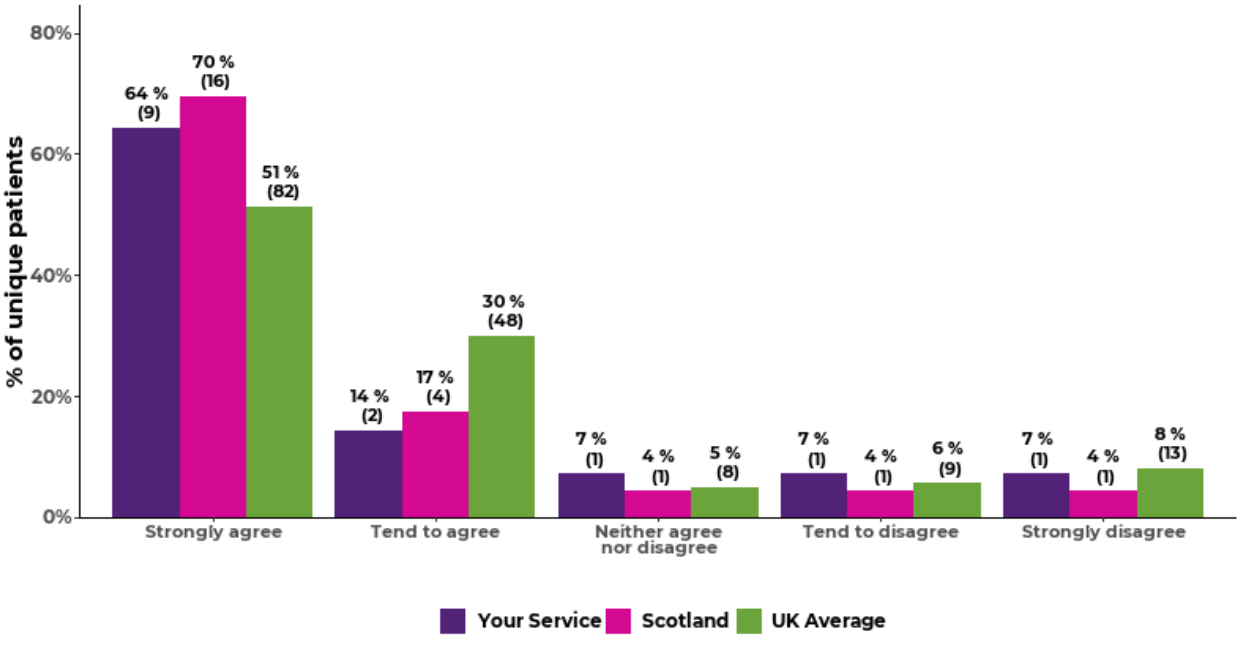
Patients = 5

4.6 Were you offered the opportunity to speak to an IBD Nurse Specialist while you were an inpatient?



Patients = 14

4.7 I was given clear information to help me manage my care after discharge from hospital including medicines, post-operative wound and stoma care.



Patients = 14

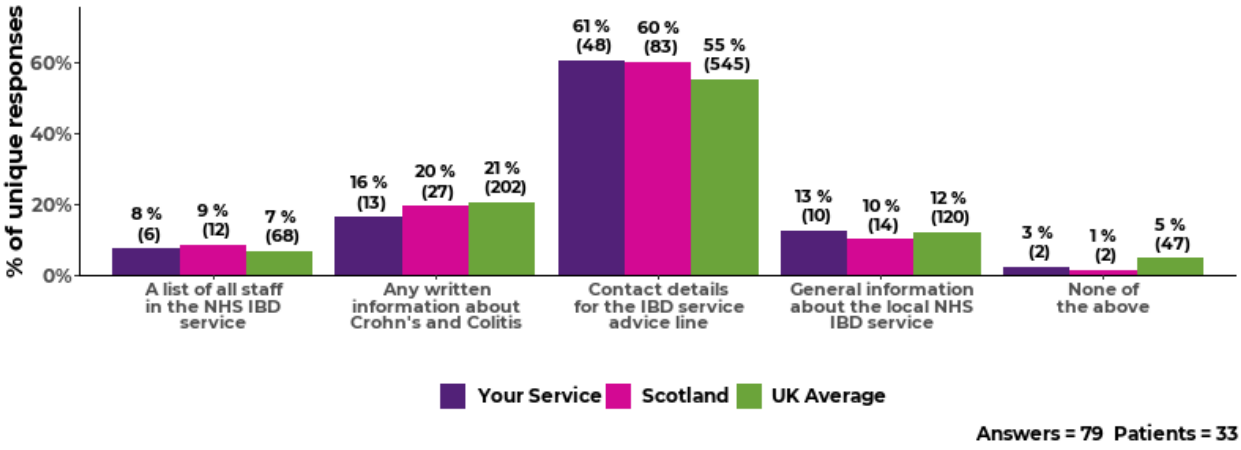
5. Ongoing care and monitoring

As IBD is a fluctuating, lifelong condition, people need ongoing care to live well with their condition. A personalised care plan will empower patients, support self-management and help primary and secondary care communicate effectively.

More information can be found on this web page www.ibduk.org/ibd-standards/ongoing-care-monitoring

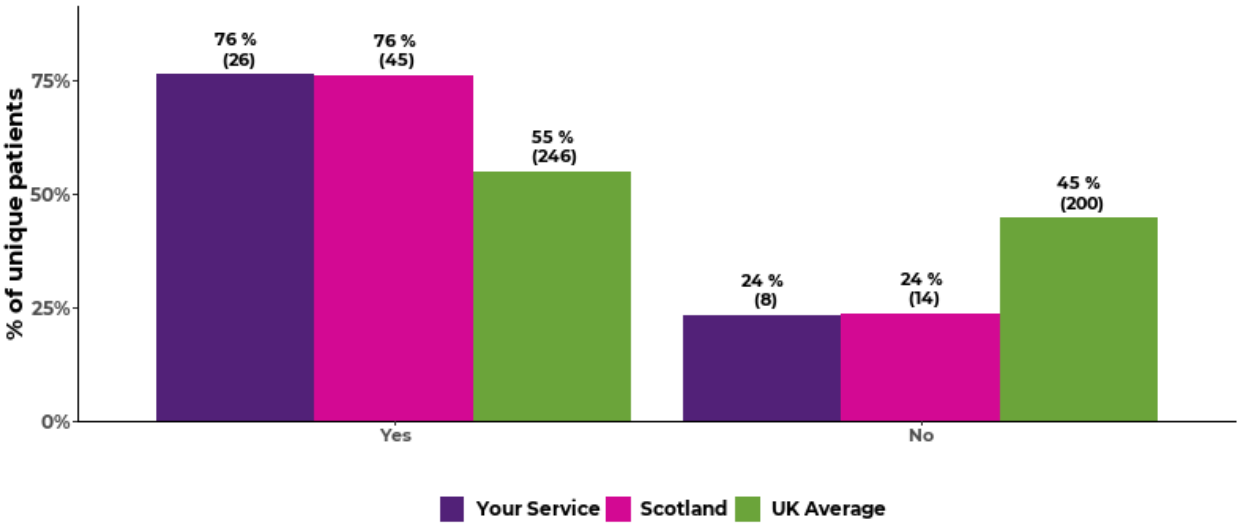
Responses included in this section are from 34 patients.

5.1 Have you been provided with any of the following?



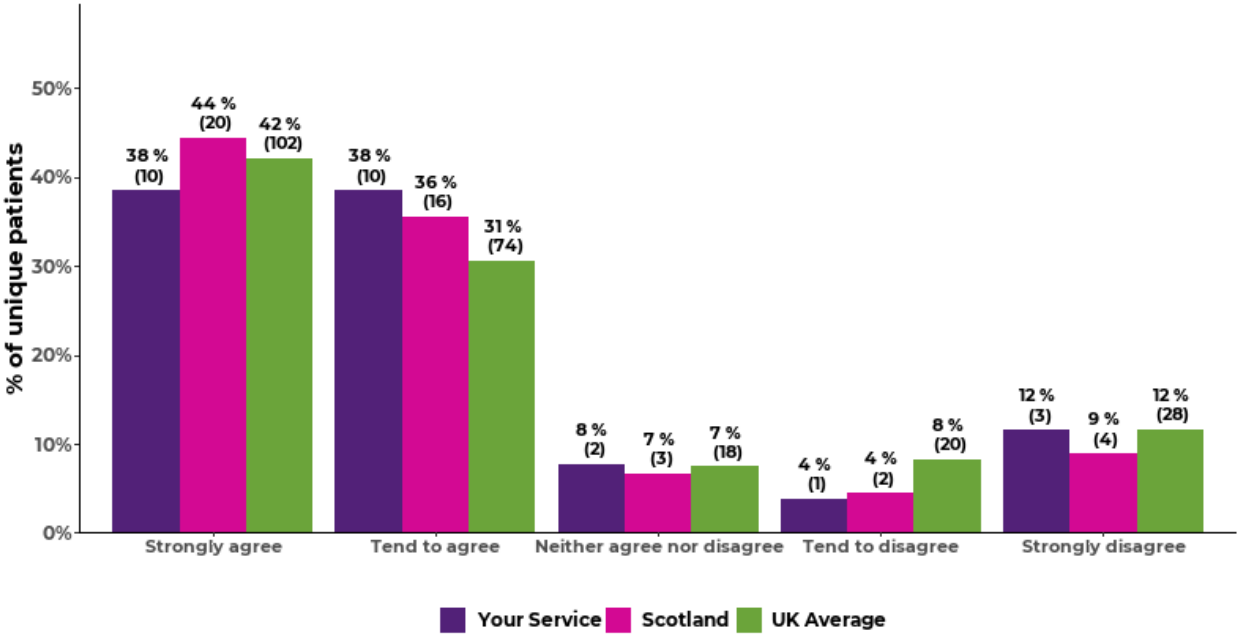
Answers = 79 Patients = 33

5.2 Have you ever contacted your IBD service advice line?



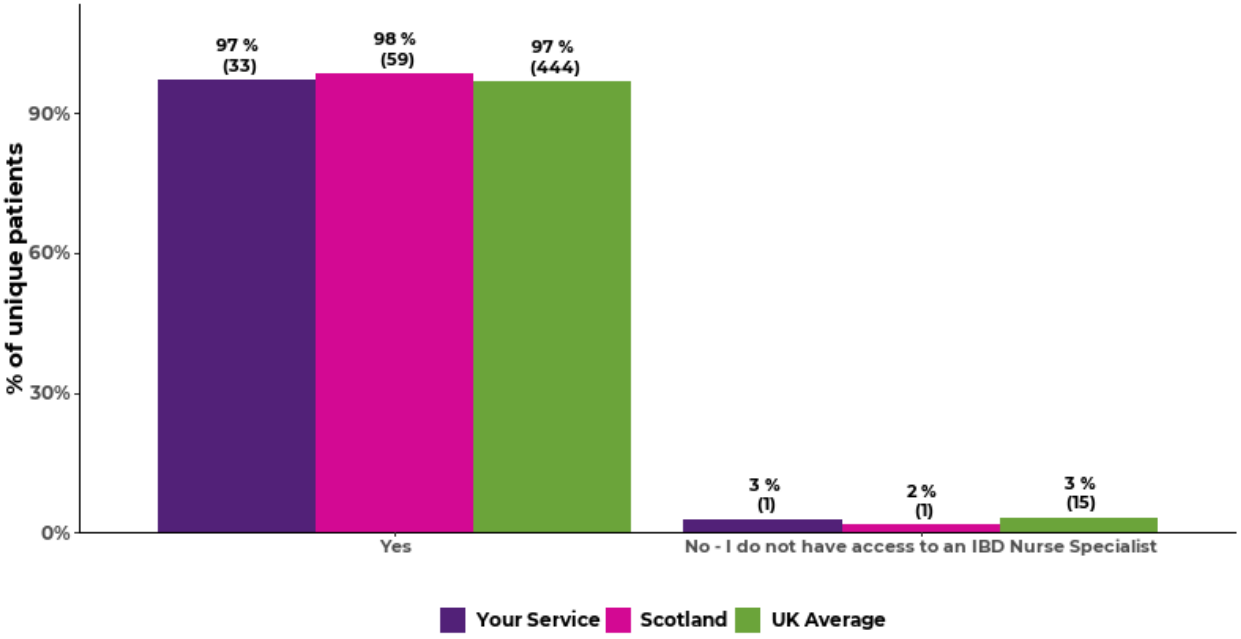
Patients = 34

5.3 When I contact the NHS IBD service advice line, I get a response by the end of the next working day.



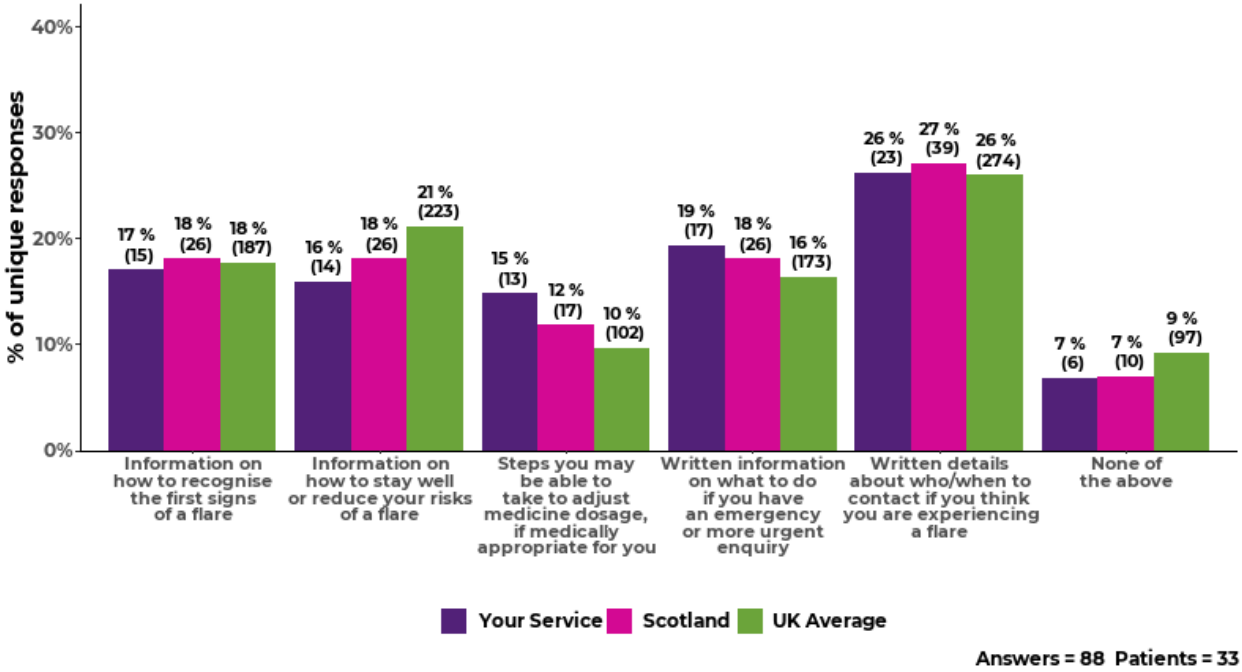
Patients = 26

5.4 Do you have contact with an IBD nurse specialist?



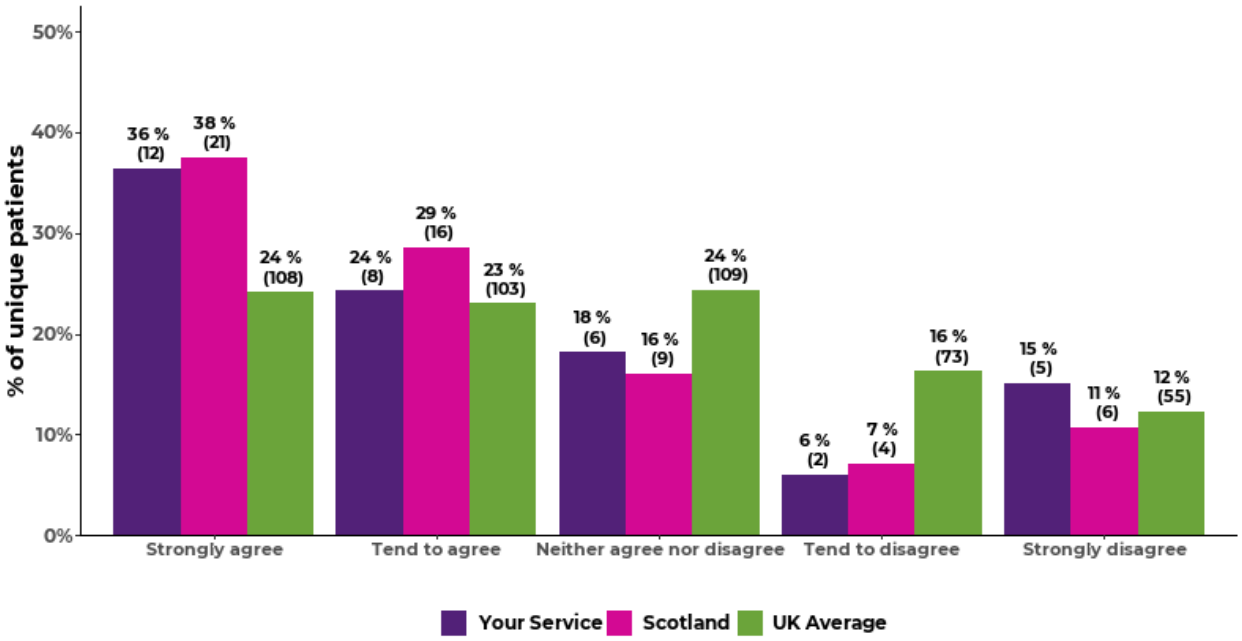
Patients = 34

5.5 Has a healthcare professional provided you with any of the following?



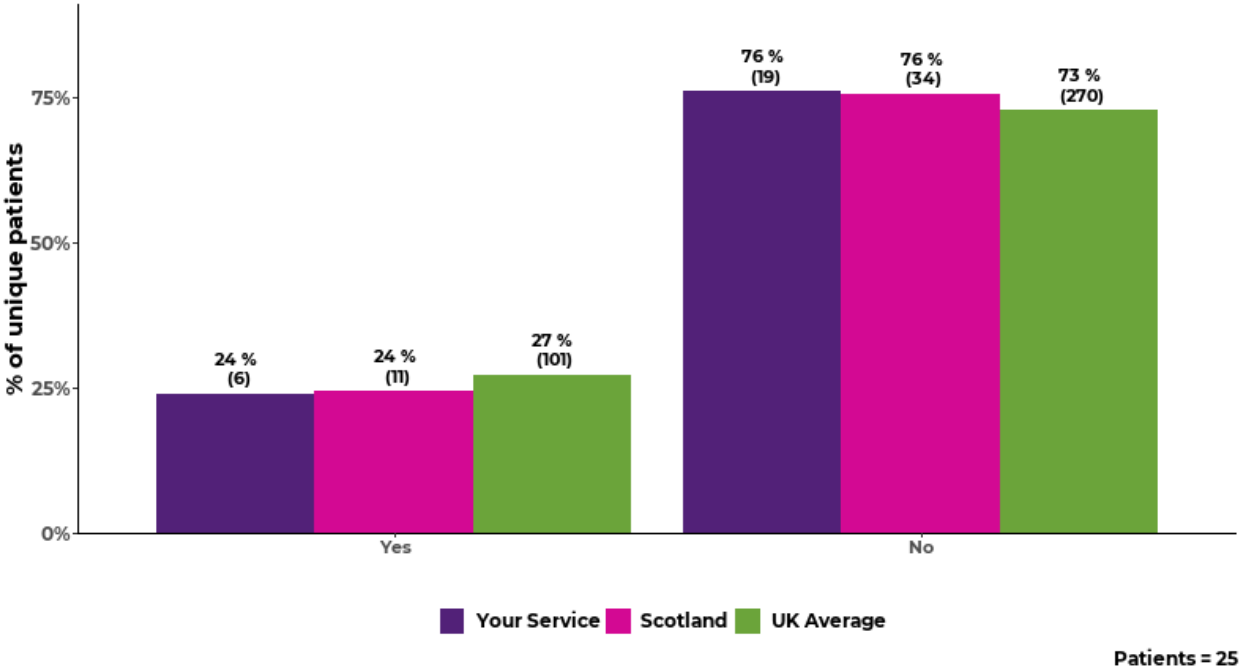
Answers = 88 Patients = 33

5.6 We discuss my wider life goals and priorities, as part of planning my Crohn's or Colitis care.



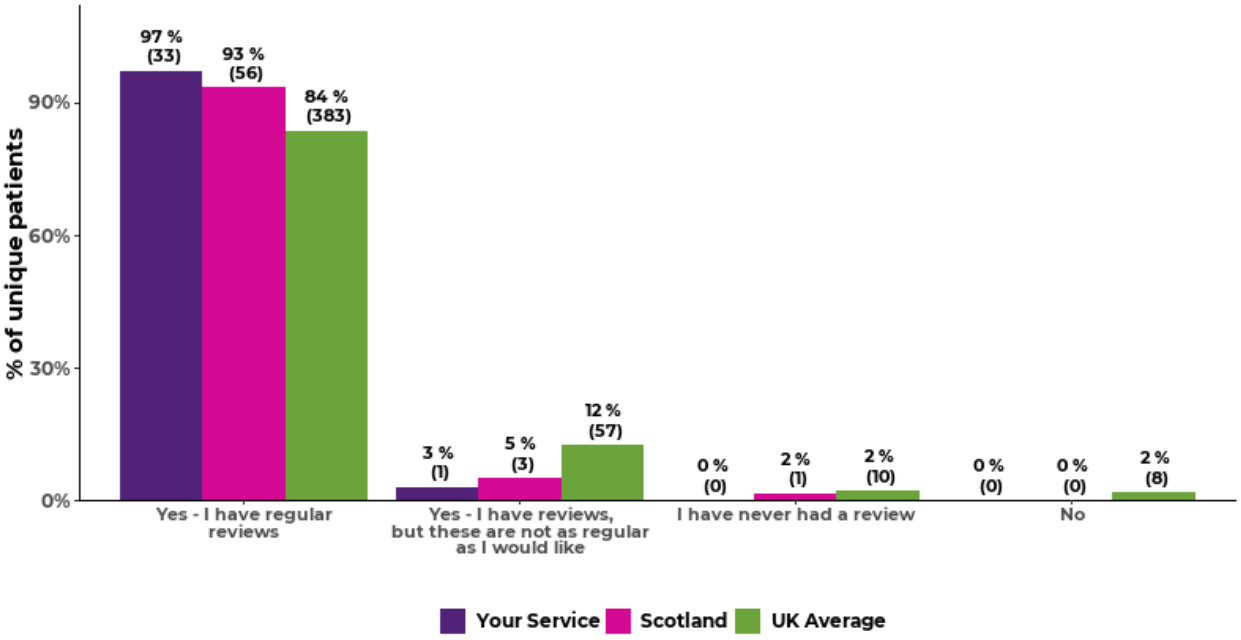
Patients = 33

5.7 Do you have a personalised written care plan?



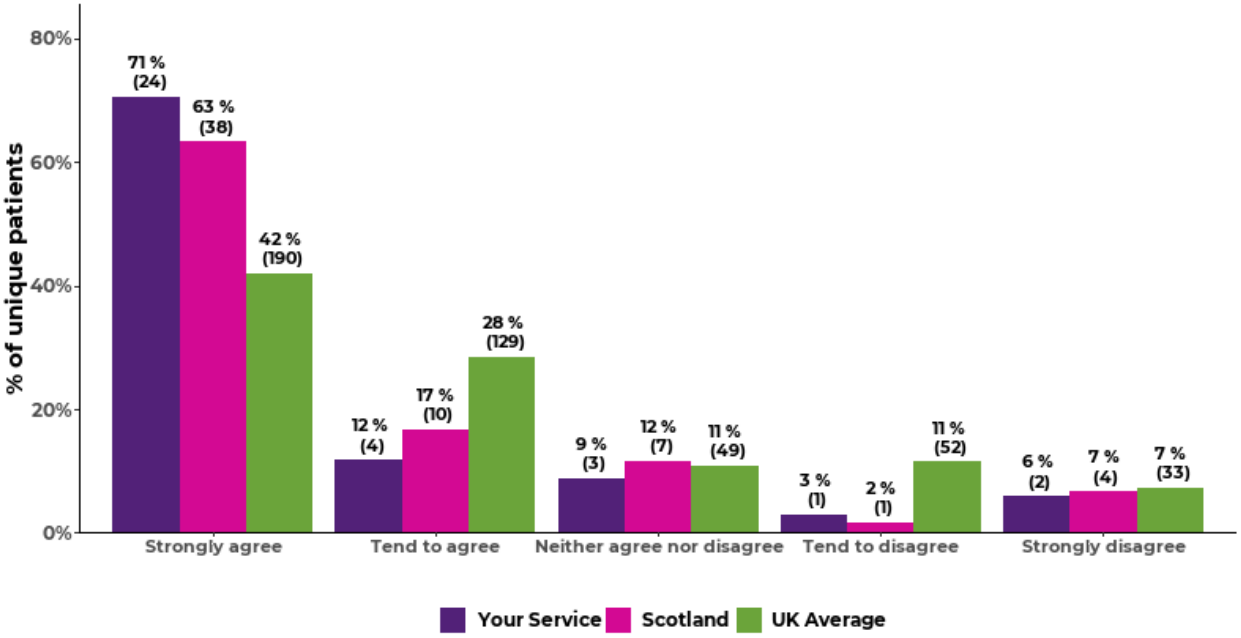
Patients = 25

5.8 Do you have a regular review for your Crohn's or Colitis, regardless of whether you are well or not?



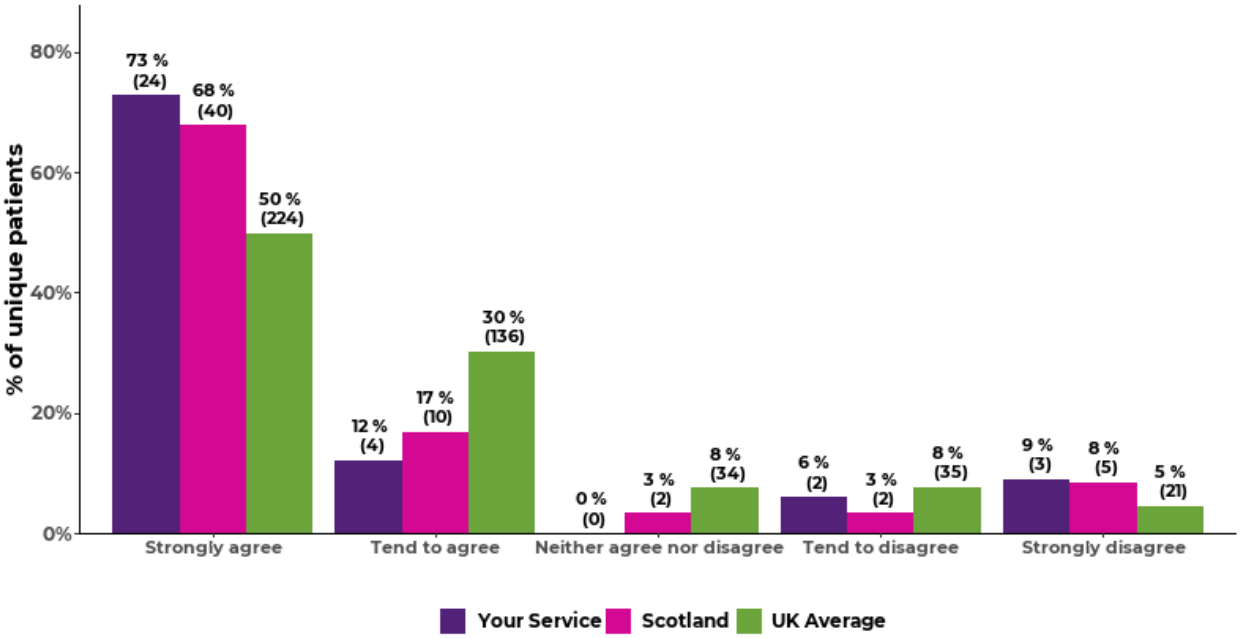
Patients = 34

5.9 During appointments, I am asked about fatigue / tiredness and treatment options are discussed to manage this.



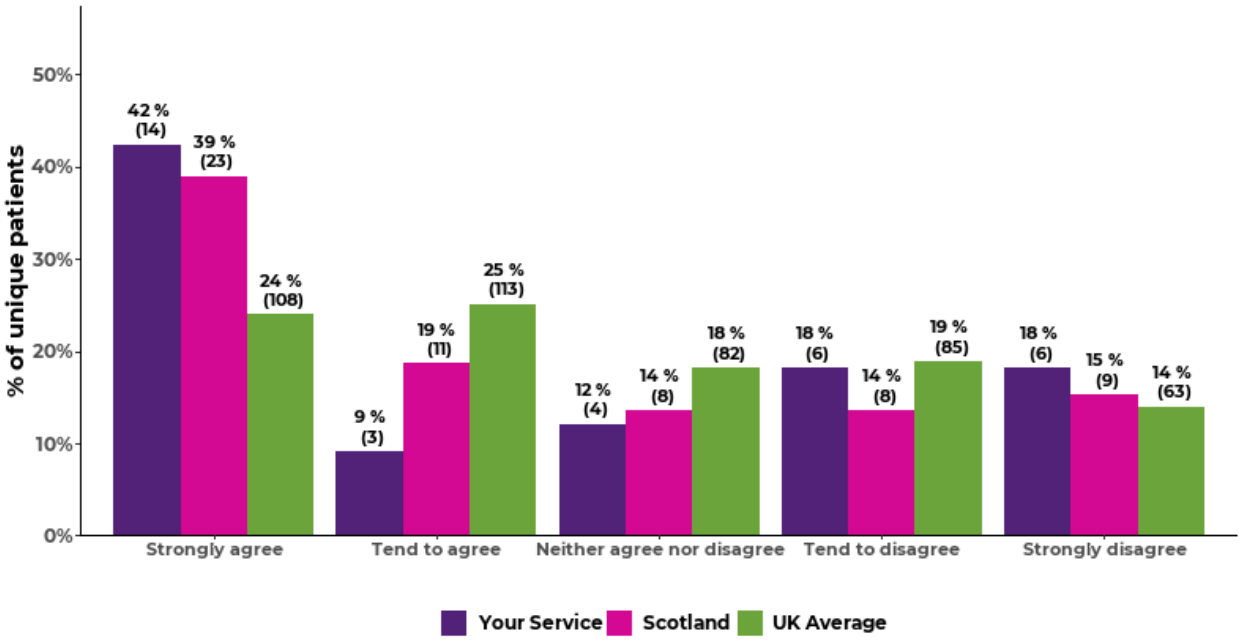
Patients = 34

5.10 During appointments, I am asked about pain and treatment options are discussed to manage this.



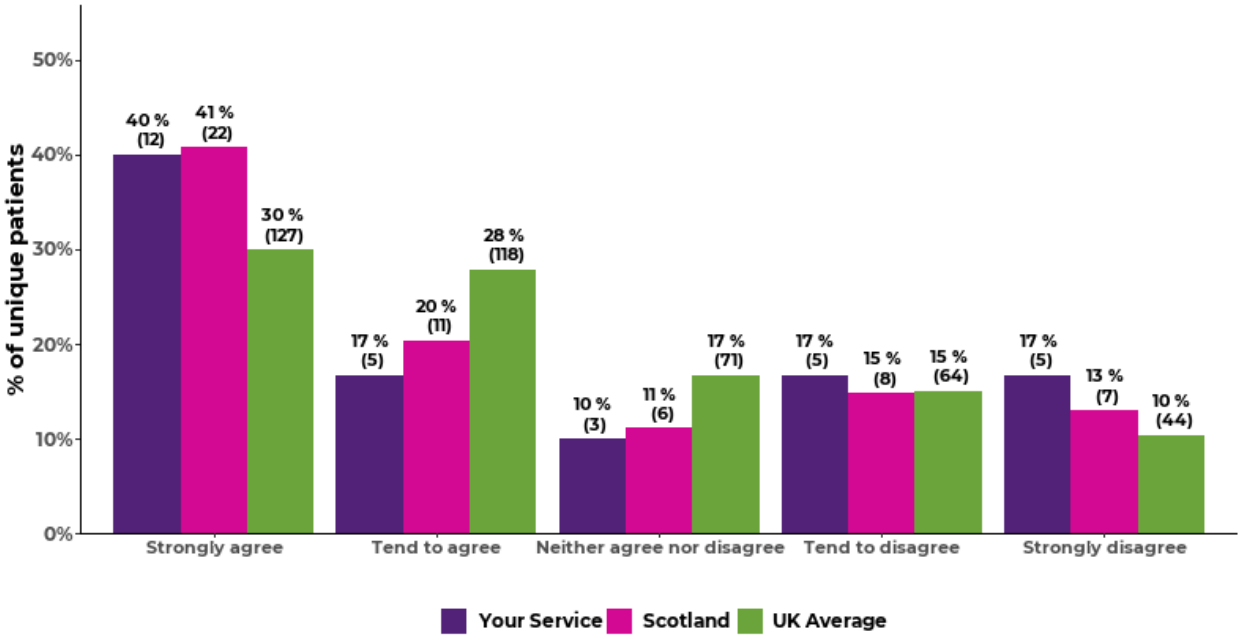
Patients = 33

5.11 During appointments, I am asked about my mental health or emotional wellbeing and treatment options are discussed.



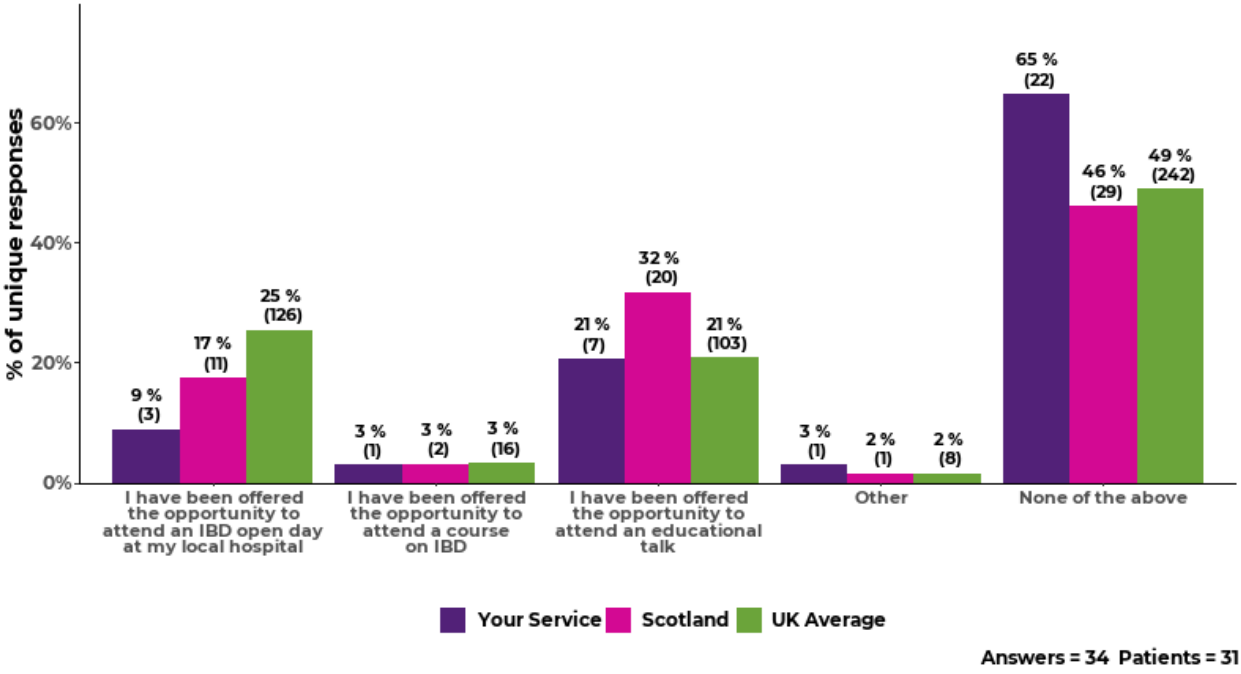
Patients = 33

5.12 During appointments, I am asked about IBD related complications and / or conditions outside of the gut and treatment options are discussed.



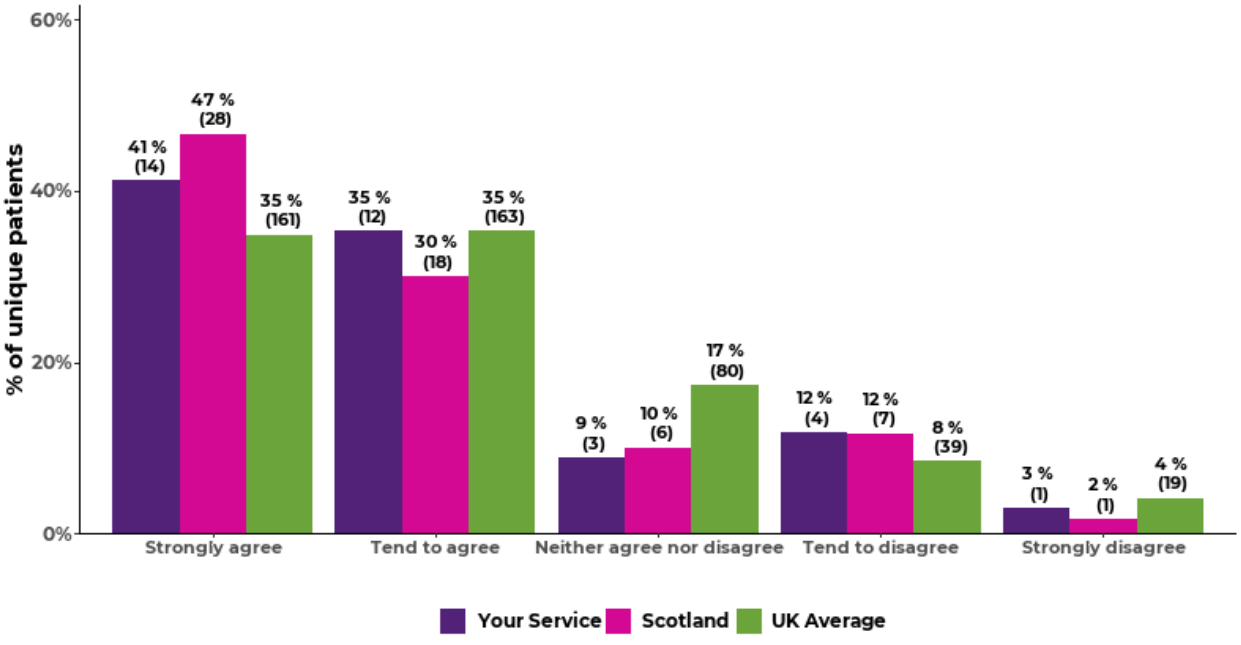
Patients = 30

5.13 Have you been offered any of the following opportunities by any NHS service to learn more about treating and/or living with Crohn's or Colitis?



Answers = 34 Patients = 31

5.14 I have the information and skills to confidently manage everyday symptoms and live as well as possible.



Patients = 34

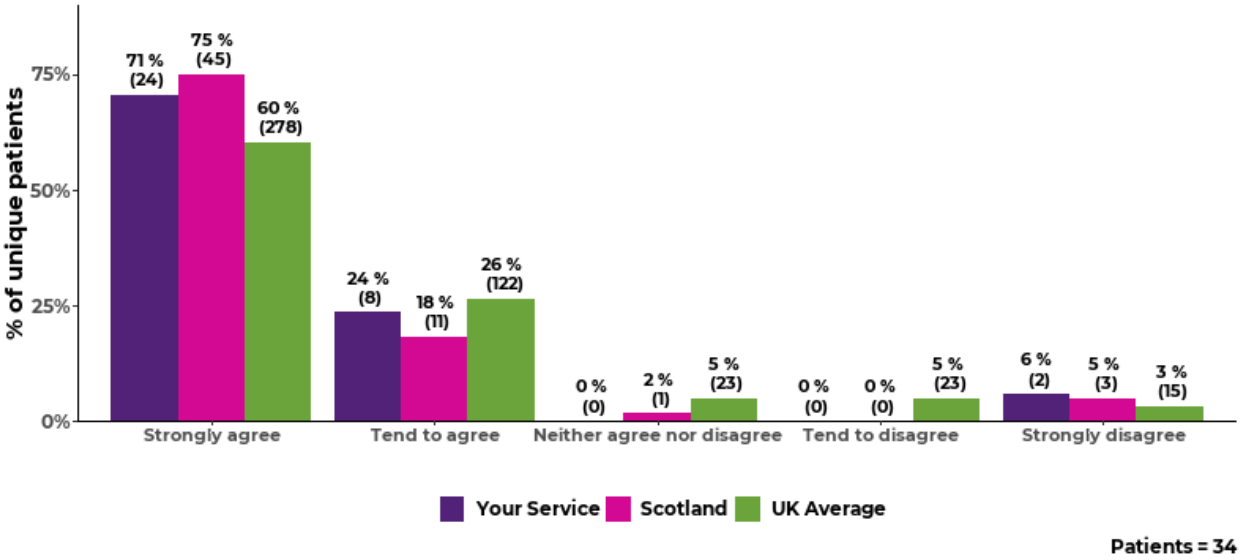
6. IBD Service

Everyone living with IBD should have safe, consistent, high quality, personalised care. A well-organised and managed local IBD service is essential to delivering this.

More information can be found on this web page www.ibduk.org/ibd-standards/the-ibd-service

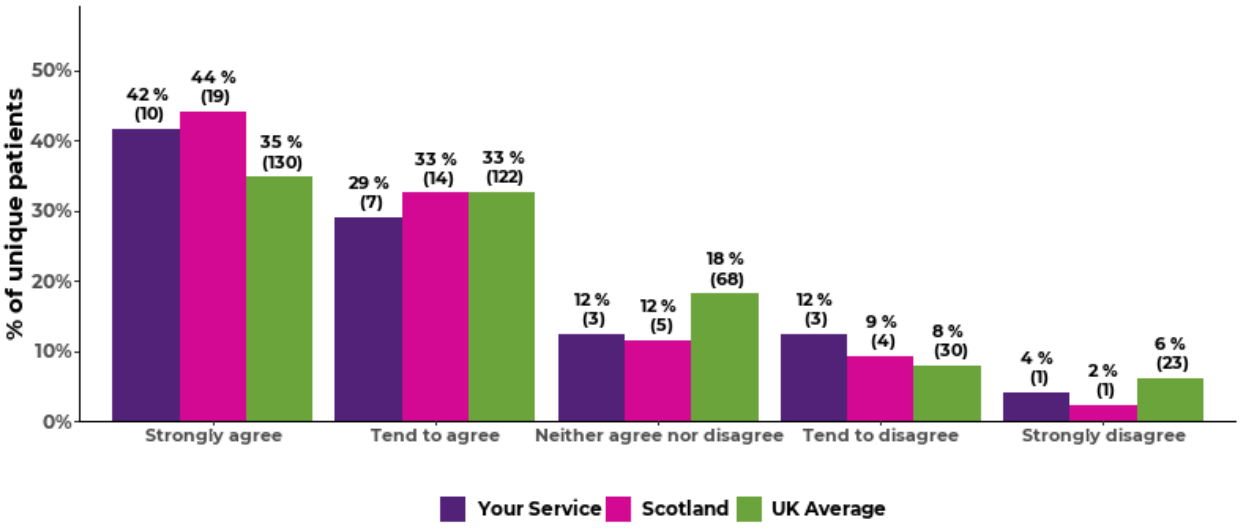
Responses included in this section are from 34 patients.

6.1 I am supported by a team of IBD specialists who help me manage my condition.



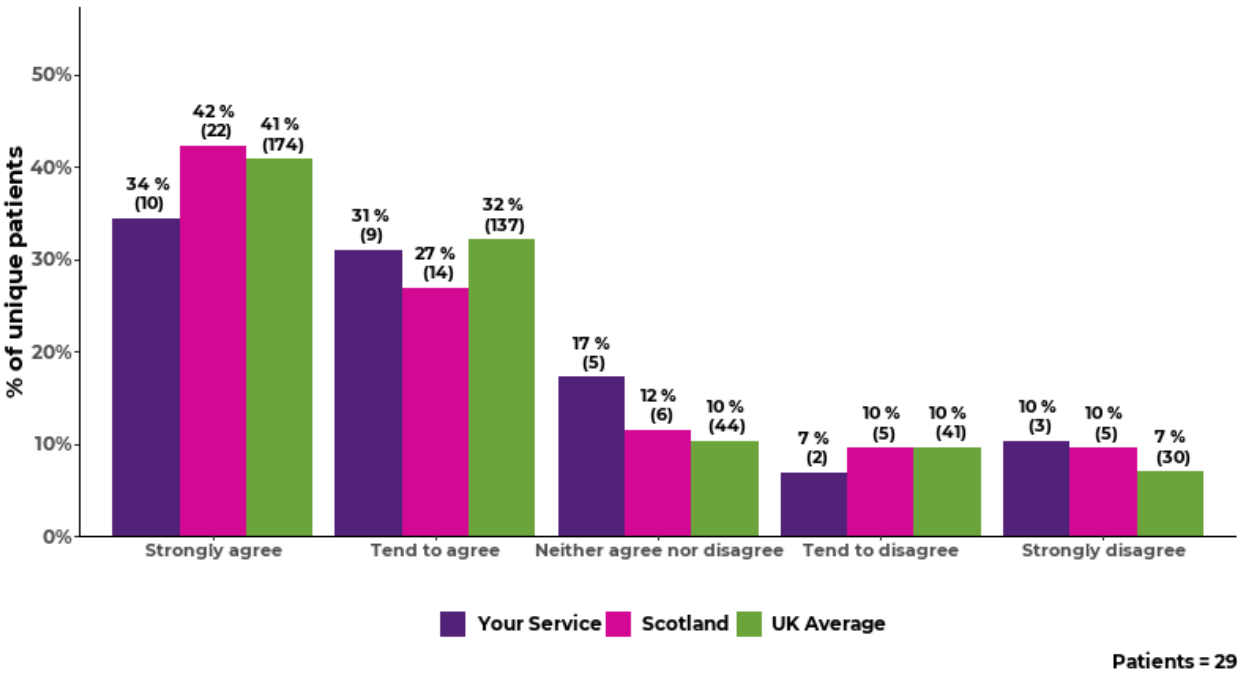
Patients = 34

6.2 My treatment and care are well-coordinated by my IBD team and any other services I see for other medical services I have.



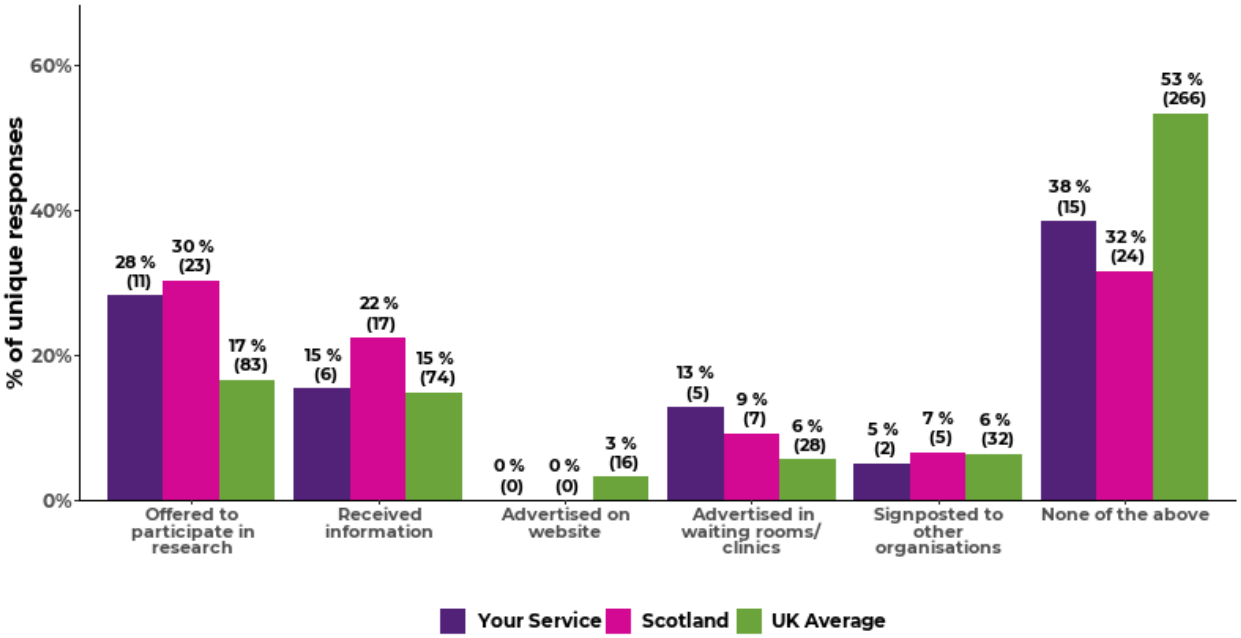
Patients = 24

6.3 I have access to specialist advice or support with nutrition if I should need it.



Patients = 29

6.4 Have you been offered any of the following opportunities to participate in a clinical trial(s) and / or IBD research?



Answers = 39 Patients = 29

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