Taking the IBD Standards forward in Scotland

"Better Care for a Better Life with IBD"

Survey Report

The Experience and Views of the NHS Scotland IBD Service From some of the People with Crohn's Disease or Ulcerative Colitis

- who use the Service -

1. Background

"Better Care for a Better Life with IBD"

Crohn's and Colitis UK are leading on delivering a programme for improving the quality of clinical care and implementing new approaches to the management of IBD as a long-term condition. The programme's objective is to develop a national strategy for IBD service improvement in Scotland, led by a national Steering Group, supported by the findings from pilots in two diverse Health Boards.

The programme is funded by the Clinical Priorities Team in the Scottish Government and Crohn's and Colitis UK.

2. Context - Scottish IBD Survey 2014

The Scottish Government's ambition is to ensure that services are co-produced with the communities they serve, build on people's assets and support the health and wellbeing of the whole person and their family.

Very early on the Steering Group decided that it would be useful and informative for the project if a Scottish wide IBD survey was undertaken:-

- To gather the views of those patients who use the IBD service to help inform and shape the nature of any future changes.
- To highlight some of the difficulties and problems that they might have experienced and capture some of their good experiences and experiences for future development

The questionnaire was completed on-line by people living in Scotland who have IBD. The survey is a snapshot of their views and experiences of their NHS health care provision – with a particular focus on their most recent flare up.

The Scottish IBD survey will further inform the pilot projects and assist them with their co-production and co-design approach which is at the heart of what they do.

We would like to thank the 777 respondents who took the time to complete the questionnaire and in so doing helped us get a clearer picture of IBD patients' NHS experiences in Scotland.

3. Methodology

The survey contains a combination of both quantitive and qualitative questions. IBD patients as well as IBD professionals were involved in the design and the trial of the questionnaire - as indeed was the Steering Group

The survey was designed to be completed on-line (survey monkey) and was distributed through the Crohn’s and Colitis UK website and membership database. To capture the views of the wider IBD community social digital networks were also used to promote the survey (Facebook and Twitter).

To ensure that there was no blurring of responses and to maintain the strict Scottish focus those who received their IBD care outside Scotland were eliminated from the survey at the first question (do you receive your treatment in Scotland?)

To ensure that the respondents’ experience was relevant in terms of capturing those with recent contact with their IBD service, those who answered more than four years to the question 8 (How long ago were you last poorly (flare up) with Crohn’s Disease or Ulcerative Colitis) were directed to the final three free text questions of the survey

The survey started towards the end of March 2013 and was left to run until the end of May. In total there were 777 respondents although not all respondents completed all the questions.

The survey is a snapshot identifying some of the key issues facing people with IBD who live in Scotland particularly on their NHS provision. Responders were self-selecting and there was no attempt to match the profile of the responders with the profile of the IBD patient population in Scotland in terms of age, gender, and social profile.

This report presents the responses to questions 1-19 which are primarily closed questions, where the respondent was asked to tick which answer most suited their circumstances

Questions 20, 21 and 22 are open ended questions and the respondent is asked to answer in free text. The analysis of this part of the survey is being undertaken separately and will be published later in the year.

4. Results

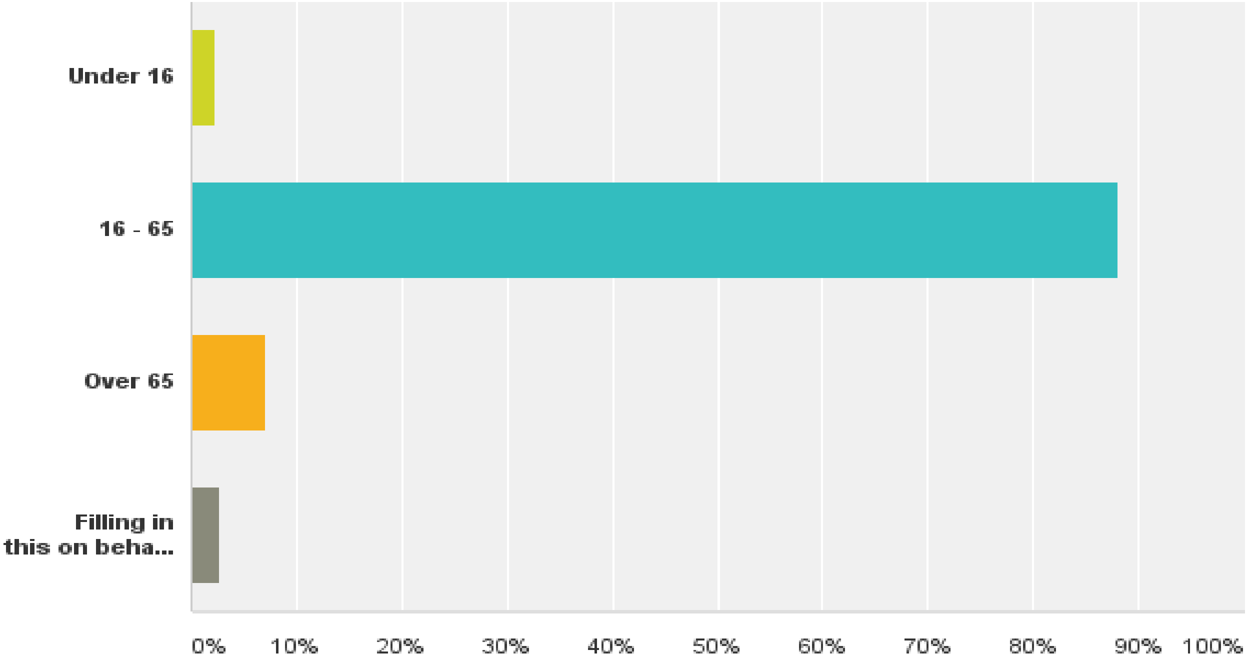
Q1. Do you receive your treatment in Scotland?

777 people answered this question. If the answer was no then the respondent was excluded from completing any further answers to the questionnaire. In total 767 of the respondents proceeded to the next question

Q2. Are you Male/Female?

More than twice as many of the respondents were women 514 (67.81%)

Q3. Age?



The great majority of respondents were aged 16 – 65 (88.06%). Whilst only 17 (2.23%) completed this said they were under 16 and a further 20 (2.62%) adults completed this on behalf of a child.

Q4. What was the year of your diagnosis?

This question was solely a textual response for people to enter their date of diagnosis. Answers ranged from 1967 to 2014.

This question drew comments regarding uncertainties, the time lapse between the onset of symptoms and delays in receiving a diagnosis.

- *It is estimated I had Crohn's for 30 – 40 years before it was diagnosed*
- *1995 - approximately*
- *It is hard to get a definite diagnosis*

Q5. Do you have an IBD Nurse?

478 (64.16%) of 745 respondents said that they had an IBD nurse.

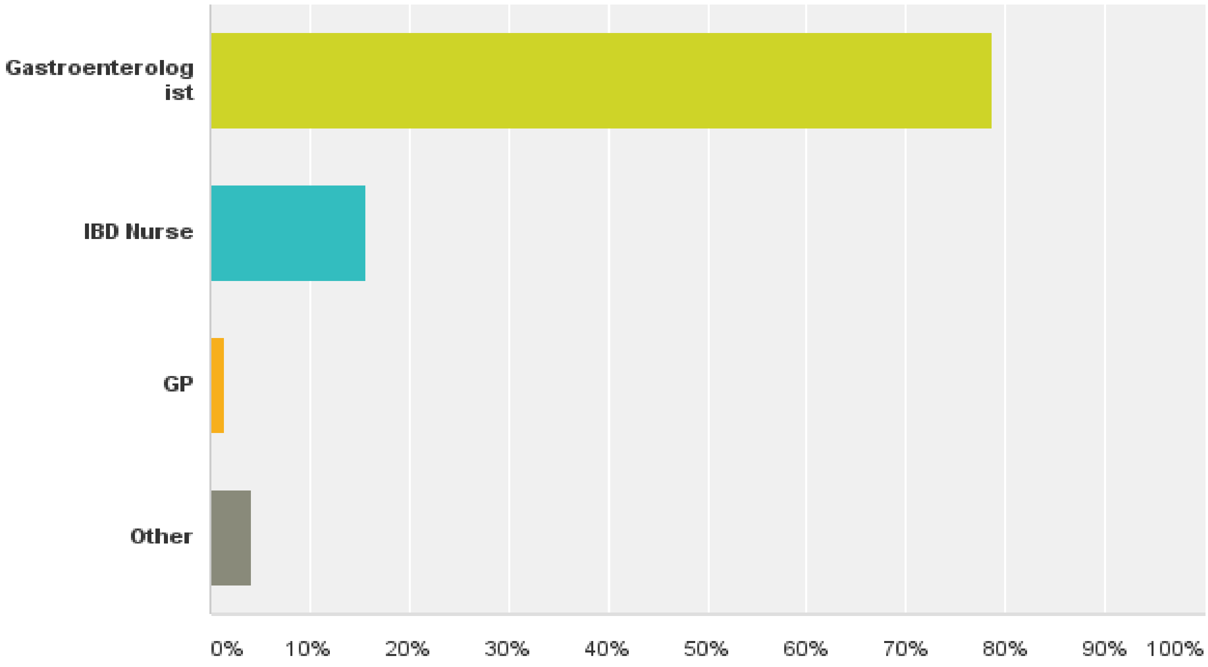
- *My IBD nurse provides fast and reliable service. Dedicated phone line is fantastic for help during flare up*

Q6. Do you have an annual review for your Crohn's Disease/Ulcerative Colitis?

Just over three quarters (78.84%) of respondents said they have an annual review. The respondents were not asked what form this review took.

- *My annual checkup provides me with both information and assurance about the effectiveness of my treatment*
- *I don't know if I do, or if I don't* [get an annual review]

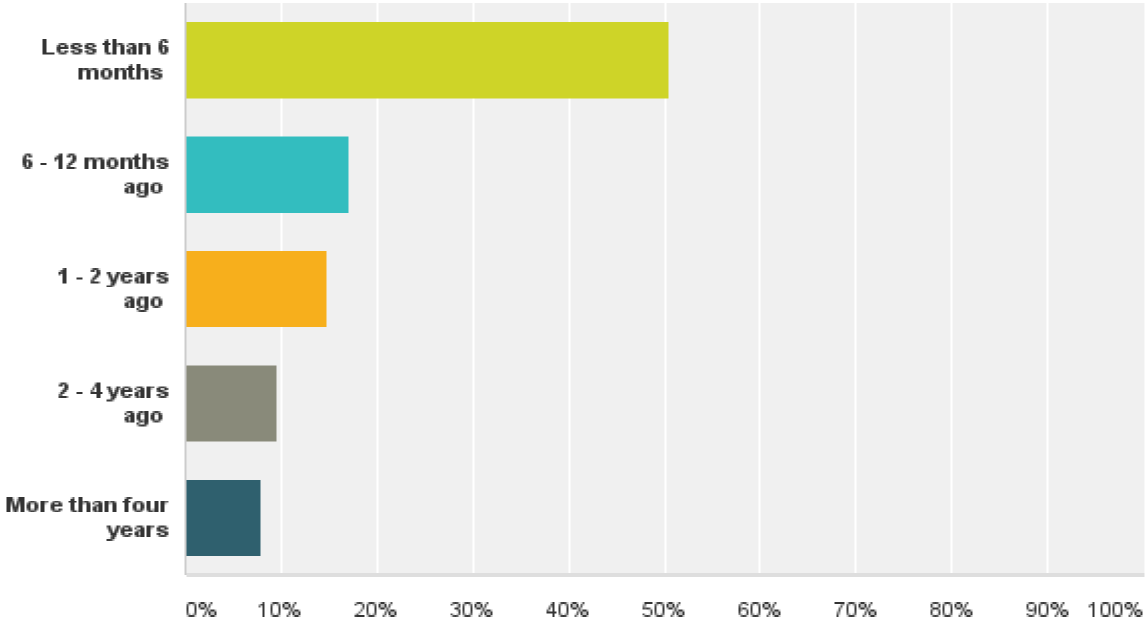
Q7. Who by?



The text responses to this final cohort ‘other’ go on to list colorectal surgeon, bupa, consultant, gastro clinic, surgeon, professor and paediatric IBD nurse

- *All depends on how busy clinic is. Could be Gastroenterologist, Dr or nurse*
- *Review is every 6 months and can be by a consultant, registrar, or IBD nurse*

Q8. How long since you were last poorly (flare up) with Crohn's Disease or Ulcerative Colitis?



The 57 respondents who answered more than four years to this question were directed to the last three free text questions in the questionnaire. This ensured that the responses to the questions about NHS care are both recent and relevant.
Just over half (50.62%) of the respondents had had a flare up in the past six months and almost 70% had had a flare up in the past twelve months

Q9. What were the symptoms of your most recent flare up?

A flare up of IBD can have multiple symptoms.
In total 3191 answers were ticked indicating that on average a flare up involved approximately 5 of the symptoms listed in the question (see graph, next page).

In addition, many refer to *overwhelming fatigue, exhaustion and nausea.*

- *It is a miserable disease that is limiting however positive one tries to be*
- *Very hard to live with during flare ups and undertake a 'normal' life as have no energy due to extreme fatigue and pain. Raising awareness amongst employers would be very advantageous so people felt more comfortable asking to work from home during flare ups when need be.*
- *It has pretty much ruined my life since I was diagnosed*

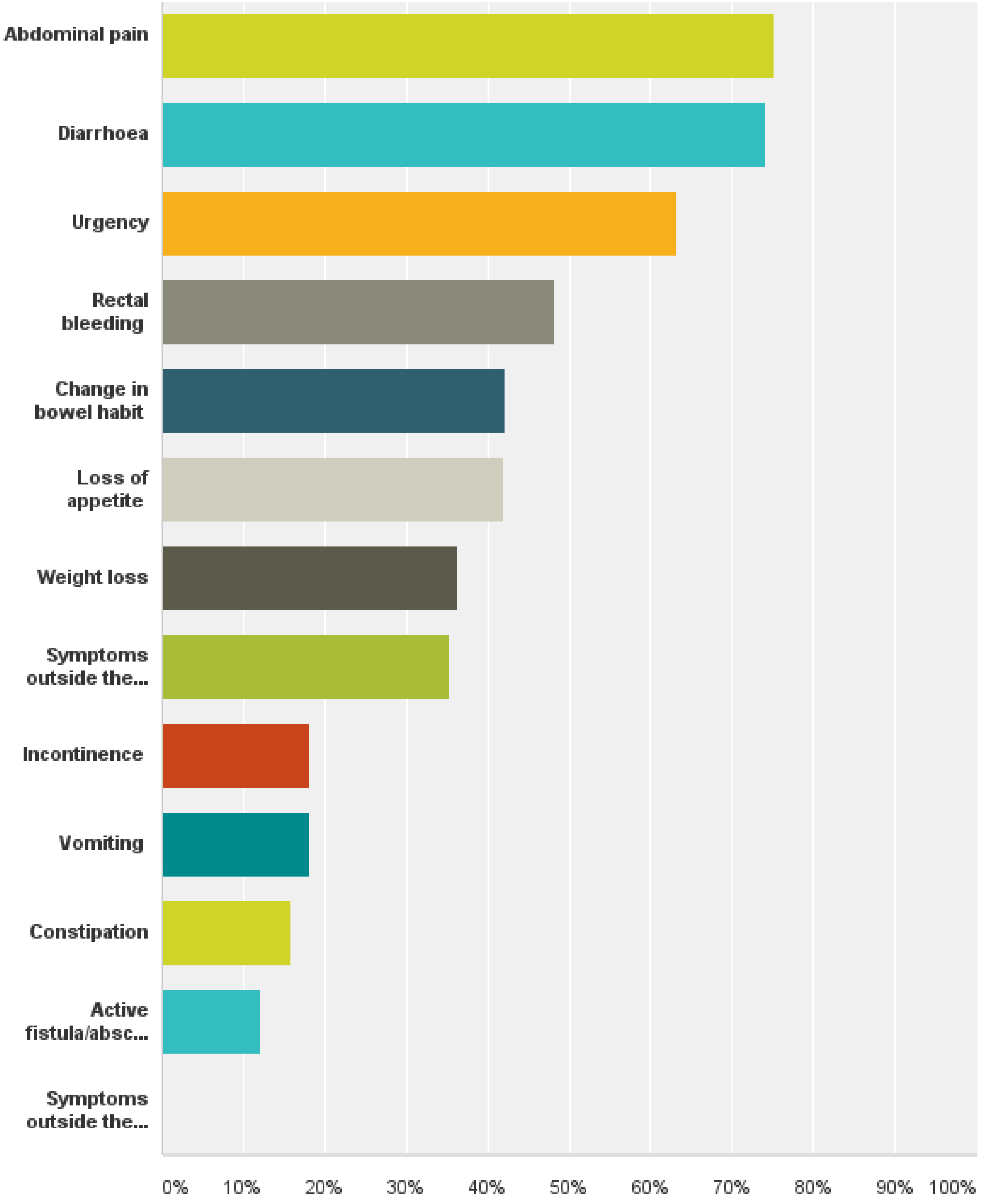
From the more moderate:

- *No symptoms at all*
- *Bad taste in mouth*

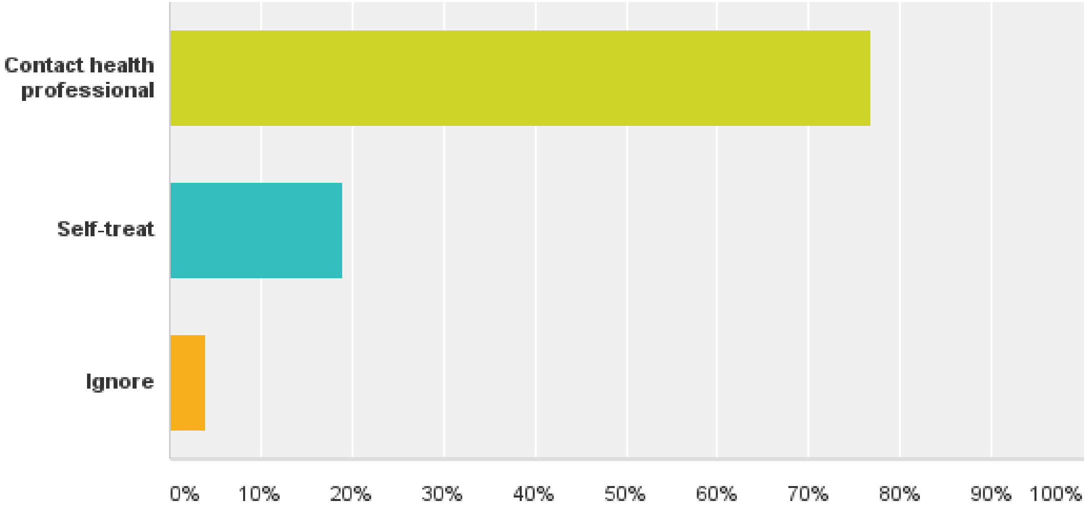
To the more severe:

- *Life threatening bleeds*
- *Collapse, severe sweats, drop in blood pressure*

What were the symptoms of your most recent flare up?

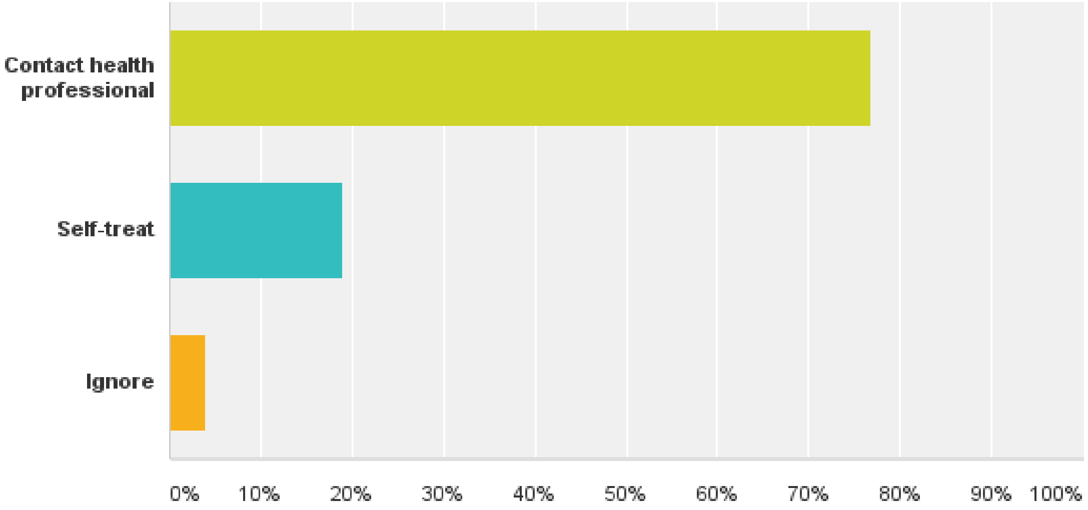


Q10 What did you do?



- *I had an appointment coming up and waited for it.*
- *I was admitted in to hospital*

Q11. Did you follow guidelines agreed with a Health Professional for your self-treatment?



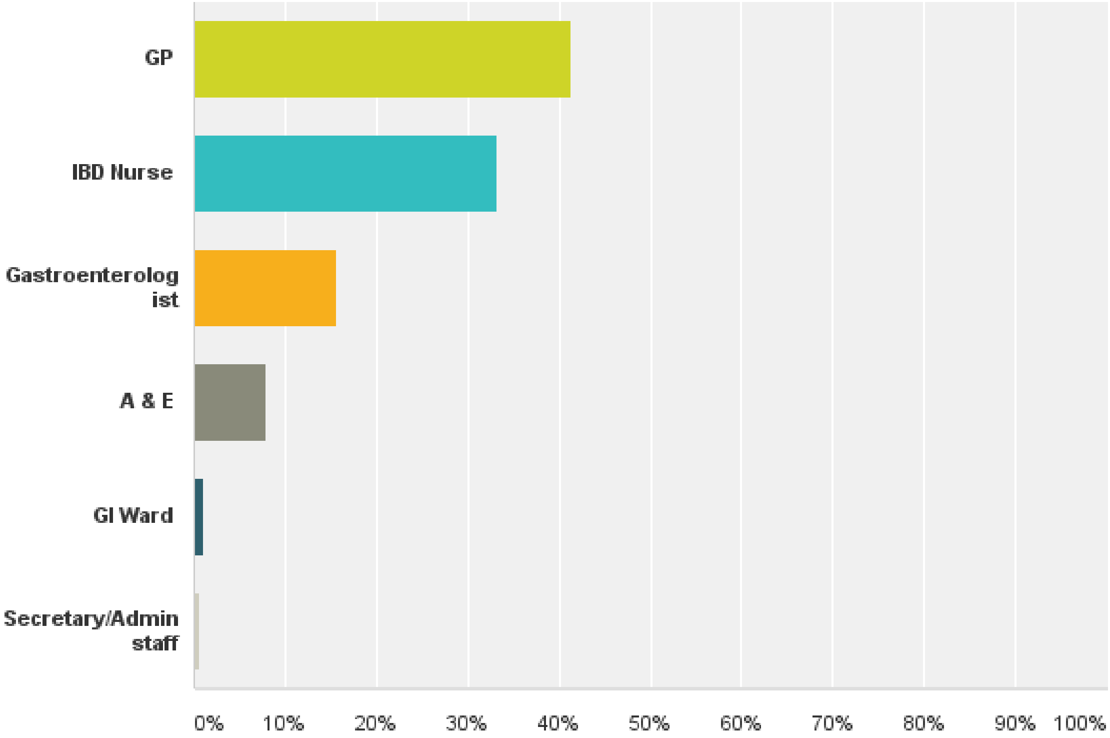
145 respondents answered this question.
Nearly two thirds (65.52%) of these followed self-treatment guidelines previously agreed with a health professional

- *Use of maximum daily permitted medicines during difficult time of flare up*
- *I have previously discussed with consultant what to do during a flare up*

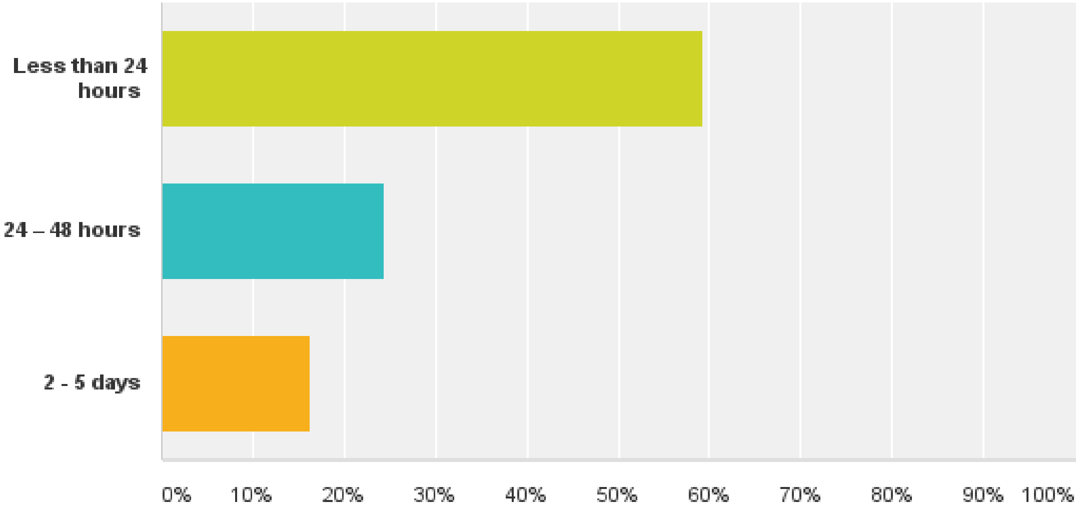
50 (34.48%) respondents said they did not follow guidance.

12. Who did you contact?

574 people answered this question.

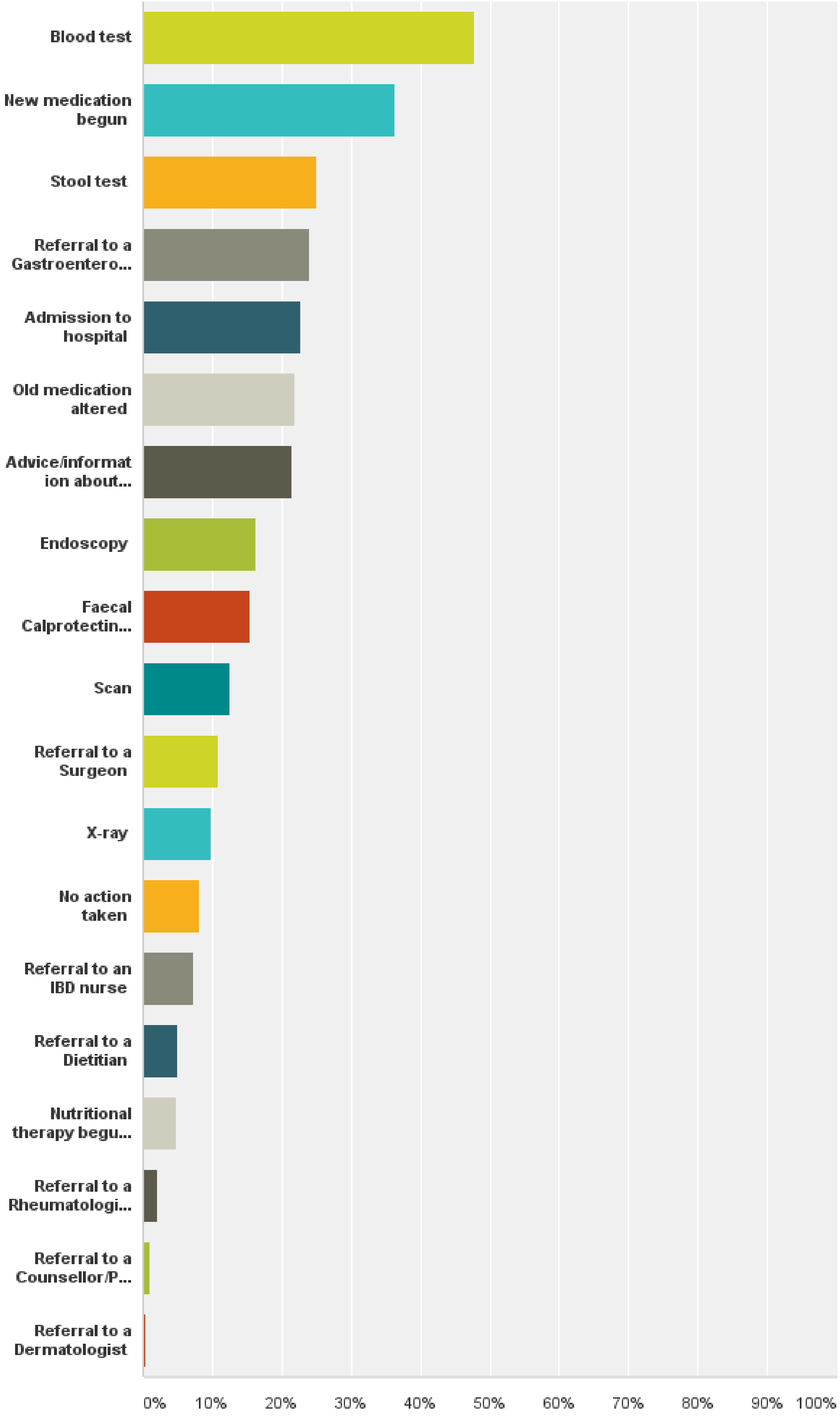


Q13. How long did you have to wait for advice, after contacting your health service?

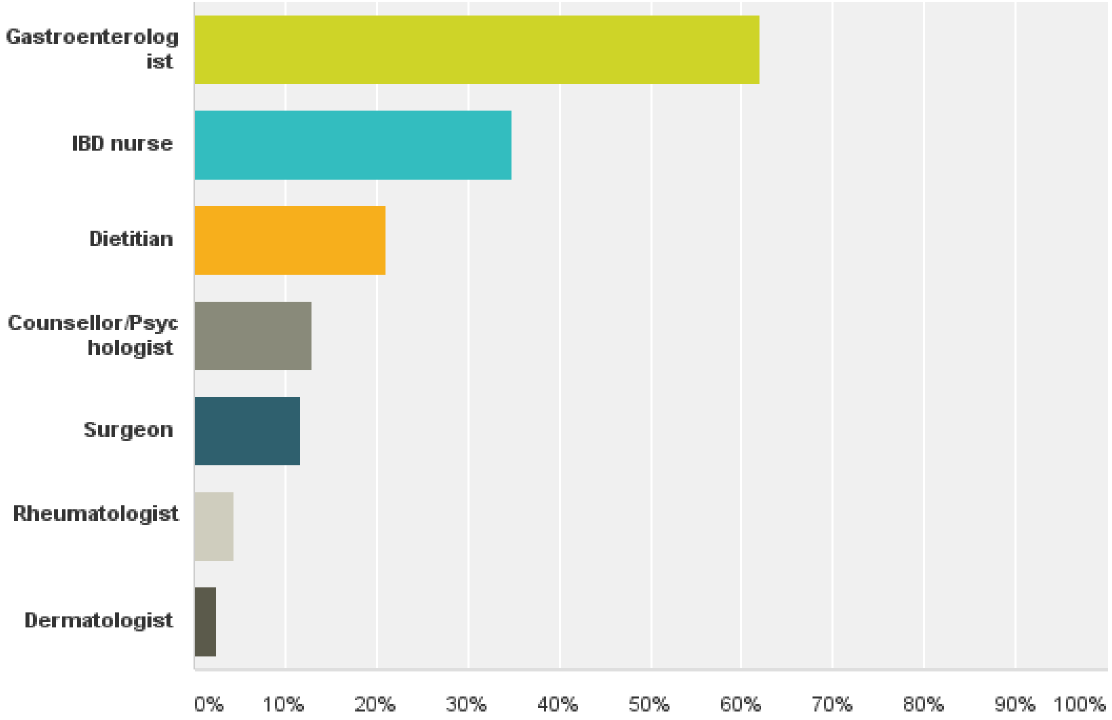


- *ALWAYS GET AN IMMEDIATE RESPONE FOR IBD NURSE*
- *I have contact number so I can contact IBD nurses directly*
- *Normally when I have to contact them it is usually the GI nurses and I usually get to speak to them within 24 hrs*
- *GP appt in a few days - several weeks before gastro appt and investigations and therefore treatment*

Q14. What action was taken?



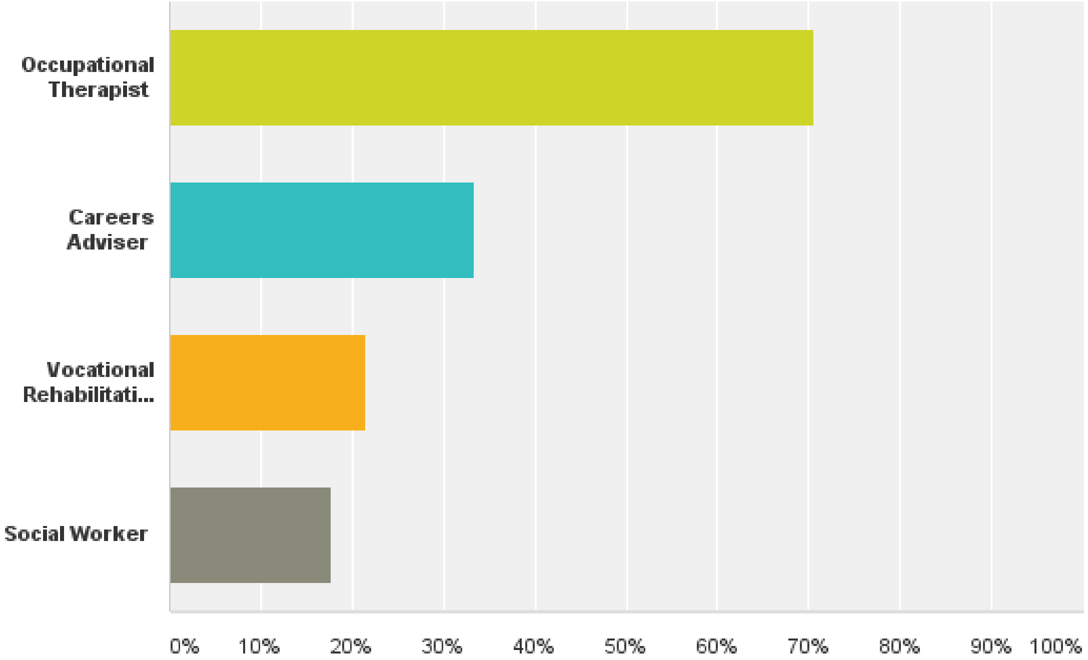
Q15. Would you have liked to have been referred to:-



One respondent replied:

- *All of the above*

Q16. Would you have liked a referral to any of the following



Many responded:

- *None of the above* or *not applicable*

And another:

- *No not at that time - once I recover*

Another stated they would:

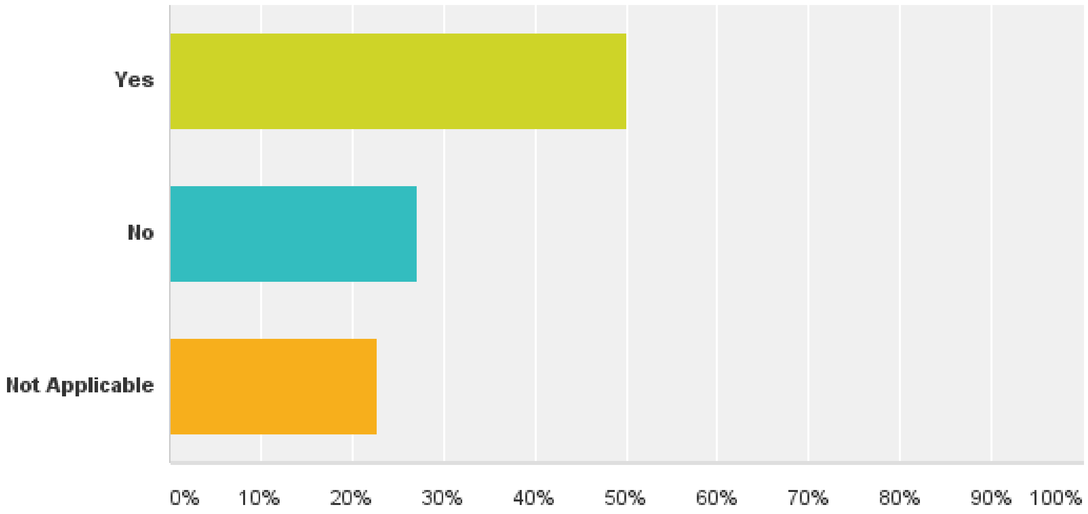
- *Like to see a pain management specialist.*

Q17. Overall how satisfied were you with your treatment?

This question was answered by 619 respondents

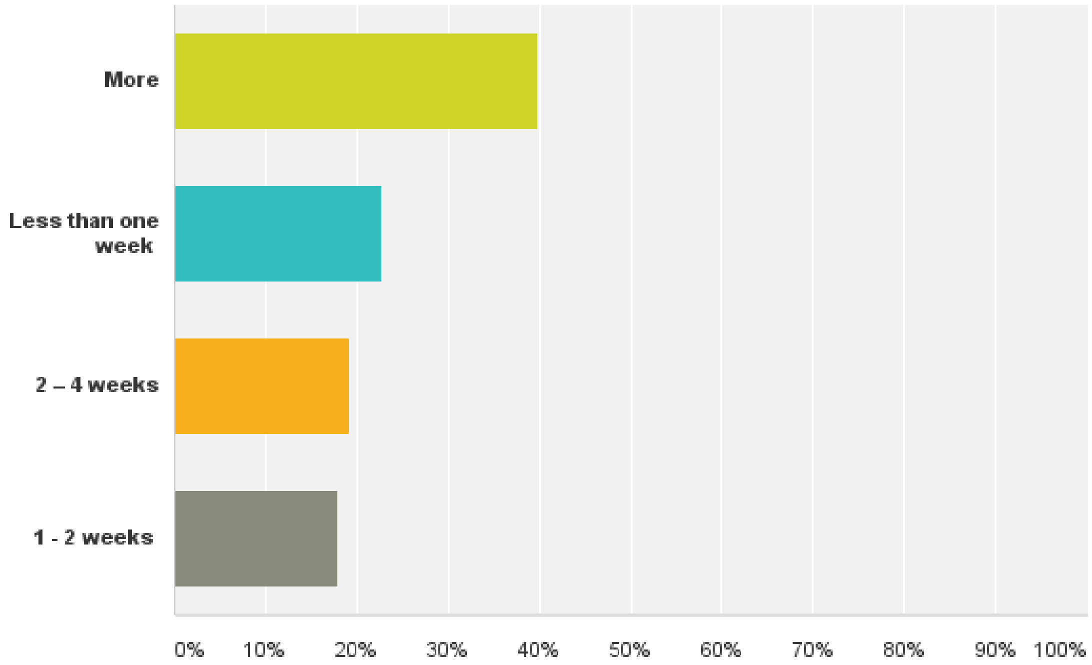
Q18. During this flare did you take time off work?

657 people responded to this question



Q19. How Long?

311 people responded to this question



The text responses to this question vary enormously. One person stated that they had

- *Not been able to work for three years*

Another:

- *Had to quit part time job*

And another

- *I have been off work since April 2013 from an operation and was made redundant from work on the August 2013 and have not worked since*

And a parent commented:

- *My daughter was off nursery for 2 and a half months*

Free text questions

The last 3 questions in the survey are free text questions ie the respondent was invited to:

Q20.Tell us two things which are good about your NHS care (609 responses)
Q21.Tell us two things which would improve your NHS care (564 responses)
Q22 Anything you would like to tell us about living with IBD (422 responses)

This qualitative data is rich with the experiences of people with IBD and living in Scotland, botl of the experiences of health care and daily living. It is being analysed by a research psychologist using SPSS software to obtain a statistical analysis. The report will be available later this year.

However an initial examination of the free text results reveals the following most frequently used words (not in any priority)

Q20. Please tell us two things which you think are good about your NHS care:-
Able to contact. Care. Check ups. Consultants. IBD nurse. Doctors. Friendly. GP; Response. Service. Staff. Treatment

Q21. Please tell us two things which you think would improve your NHS care:-
Advice. Annual Review. Appointments. Care. Consultants. Diagnosed. Diet. Hospital. IBD nurse. Medication. Treatment. Understanding. Waiting

Q22. Anything else you would like to tell us about living with IBD?
Condition. Disease. Fatigue. Flare. Illness. Public toilets. Symptoms. Tired. Tiredness. Understand. Disabled.

See A**ppendix 2** for a few of the comments as an example of the responses received:-

5. Further analysis on the impact of having an IBD nurse

The responses of those who said they had an IBD nurse were cross tabulated with those who said they did not.

Respondents who said they had an IBD Nurse (Q5) also said that they were more likely to have an annual review (86% compared with 66% of those who do not have an IBD nurse). The review is slightly less likely to be undertaken by the gastroenterologists if the respondent has an IBD nurse (74% compared with 91%)
Further research is needed to be confident of this relationship, as free text comments indicate some uncertainty about the definition of an annual review.

Patients with an IBD nurse are most likely to contact their nurse in the event of a flare up (48%) and less likely to contact their GP (30%) The GP is most likely to be the first point of contact for patients who don't have an IBD nurse (66%)

In the event of a flare up respondents are more likely to follow self-treatment guidelines if they have an IBD nurse (73% compared with 58%)

Those with an IBD nurse are more than twice as likely to be very satisfied with their treatment (52% v 23%) and half as likely to be very unsatisfied (4% v 7%)

6. Conclusions

The purpose of this survey was:-

1. To identify and raise awareness of some of the key issues facing people with IBD who live in Scotland, particularly their views and experiences of their NHS provision.

To this end in May 2014 Crohn's and Colitis UK held a successful awareness raising event in the Scottish Parliamentary Building by patients, clinicians, nurses and MSP's, where Health Minister Michael Matheson MSP told an audience that he anticipated the work of the Scottish Service Development Steering Group on Inflammatory Bowel Disease would lead to improvements in services across Scotland.

Crohn's and Colitis UK will continue to publicise the results of this survey to raise awareness of some of the key issues facing people with IBD who live in Scotland, particularly their views and experiences of their NHS provision.

2. As part of the 'Raising the IBD Standards in Scotland' Project, to validate the direction (in terms of service improvement) that the project is taking - by consulting with a wider audience.

This survey provides confirmation that there are many people with IBD living in Scotland whose NHS service provision falls below that outlined in the IBD Standards.
Prompt diagnosis, readily available information, quick access to advice and support (particularly when suffering from a flare up of the condition) are issues that are frequently raised.

3. To identify if there are any areas of NHS service provision which the Project has overlooked or not given sufficient priority to.

In terms of gathering Patients' Priorities then the analysis of the free text responses to Questions 20/21 & 22 is important because this is the part of the survey where patients are able to express what is important to them in terms of What is Good About Your NHS Care; What Would Improve Your NHS Care and What it is Like Living with IBD.

The Pilot Project Steering Groups (NHS Highlands Health Board (HHB) and NHS Greater Glasgow & Clyde Health Board (GGCHB) will consider the results of this survey in the light of their proposed improvements and make any necessary amendments in their direction of travel.

Peter Canham; Patient Involvement Adviser; Crohn's and Colitis UK
Shona Sinclair; SKS Scotland
August 2014

Appendix 2

Q20.Tell us two things which are good about your NHS care

- *My GP and Gastroenterologist are very good at looking at my health as a whole and factoring in my disease with other things. Also, my GP has been a convenient and helpful way of getting temporary steroid treatments to get a flare up under control.*
- *Always able to speak to IBD nurse. If not available will always return calls. Appointments made at clinic are almost always made at a date and time suitable to allow parents to arrange time off from work as need to travel distance to hospital.*
- *I find it very hard to think of anything! The only thing I can say is the IBD nurse tried her best for me but the medication is not working and I have been referred for surgery*
- *Care between GP and Gastroenterologist is seamless, in that all done according to Gastro's guidelines & a clear route if I need to to return to hospital sooner.*
- *I have been diagnosed and treated in a fairly short time. I have been included in the treatment process and consulted throughout.*
- *Good relationship with my consultant, feel confident he supports me and wants to find the best ways to manage my illness. Very closely monitored and listened to*
- *After many years of dealing with UC I have finally got a GP who understands the illness and flare ups well. He has been excellent. It really helped knowing I had the support of my GP during my last flare up. He listened, was supportive and understanding. I had never really had that level of care before and it really made a difference. He has got me back on track with my regular bloods.*
- *Having an IBD Nurse Specialist is just an incredible service. They know me well, I'm seen quickly and because my Crohn’s is severe I am seen and treated much more quickly than when my hospital didn't have a nurse specialist. I feel so grateful to have them there.*

Q21.Tell us two things which would improve your NHS care

- *The idea of shared care across GP and Gastroenterologist is good most of the time, but during severe flare ups or medication changes there aren’t enough communication or clear direction from the two.*
- *GP's seem to have no understanding of condition. More training required.*
- *Pain management. I was in severe pain for 6 days. Reluctant to give morphine which was given after 6 days of severe pain.*
- *As I live in* [redacted] *I had to fly to* [redacted] *for scans and treatment. In 1 week I had an MRI scan and a bone scan. Both on different days, so I had to take 2 days off work and the NHS had to pay for 2 sets of return flights. Neither department would change the date of my scan to prevent this from happening*
- *I would like to have access to a counsellor, someone to talk to. When I am in hospital the quality of food could be greatly improved - not good in general and particularly someone with Crohn’s.*
- *On admittance to* [redacted] *it would have been helpful if I had been offered correct diet/dietician input as the food on menu not suitable for condition. Was offered nothing other than menu! Staff were told could eat items on menu and did not do anything about it. One nurse told me it was only a little milk and proceeds to pour on my Rice Krispies! Quite obvious she had no understanding of how ill that would make me.*

- *Access to psychological therapy to help manage emotions and transition of illness*

- *Not having a round trip of 160 miles for a consultation*
- *Try to get GP's to think beyond 'he does back in for persistent diahorrea again, let's treat the diahorrea' rather than 'why is it happening again so soon?'*
- *More funding to support the IBD helpline, which was swamped with calls and had to be temporarily suspended in August 2012.*
- *At my last flare, the A&E didn't even consider my Crohn's was causing the pain in my abdomen, so it went untreated for the whole 2 weeks stay*
- *Cover over the weekends and a faster diagnosis! I feel my GP ignored key signals of my condition and was too quick to put it down to food poisoning or IBS and I had to wait months for an endoscopy to confirm the diagnosis while having a flare up.*
- *Local outreach clinics would be helpful*
- *GP's need more education with Crohn's as I had rectal bleeding and for about two years I was diagnosed with IBS until I had a flare up and my cramps were so bad I struggled out of bed and I was supposed to have been referred before the severe flare up, but it never went through until I was in so much pain and had other symptoms. I struggled to get my children up for school or get out of bed*
- *Adult faecal calprotectin tests available on NHS, after transition from paediatric care. Faster communication from hospital to GP regarding clinic blood test results and treatment changes through an integrated IT system*
- *More information about self-care for U/C*

Q22 Anything else you would like to tell us about living with IBD?

- *IBD has left me feeling a complete waste of a man. I spent years building my driving schoo and 6 weeks after quitting smoking fell ill. Got diagnosed within 6 months remained ill for 18 months, lost driving school. Abandoned plans to buy new house which my wife desperately wanted. Finally got into remission for 12 months, spent thousands rebuilding driving school over last 6 months. Finally rebuilt all was going well. 3 weeks ago flare up again. PS Also on anti-depressants.*
- *Tiredness is a killer and can leaving me feeling low and emotional.*
- *Lots of accessible toilets are helpful, I usually end up running into pubs where I know there are lots of toilets.*
- *For me by far the hardest part has been urgent bowel movements many times each day. Especially all the years before I was diagnosed with Crohn's when I felt it was all my fault. When I was diagnosed the hospital didn't tell me about Crohn's and Colitis uUK, it was an acquaintance who also has Crohn's. I had always felt such a failure with my urgent bowel movements, it was wonderful to read your literature and find that was a normal part of IBD. I told my GP and he promised to put some literature in the waiting room - it has never appeared. I don't go on foreign holidays as it was just too difficult.*
- *At my surgery, Gps only have very limited knowledge and are reluctant to arrange a consultant appointment. They do not get any follow up information from my visit to the consultant.*
- *Recognition by employers - better public education.*
- *Think it's very unfair that someone with, say asthma gets DLA. They only might have an asthma attack once in a while. Whilst someone with IBD is told they can't get the benefit because our disease goes into remission. As you know we always have symptoms only we don't class them as severe all the time.*

- *It's hell at times. The IBD and associated problems I have: arthritis, osteoporosis, peripheral neuropathy, gastritis, low iron levels, low white blood count, low platelet levels, etc. But if you have good health professionals, they can help make it better for you. And when the good times come, make the most of it.*
- *It is important to feel empowered to do as much self-management as possible and to be listened to when you identify things, e.g. dietary triggers ongoing use of Modulen that work for you as an individual. A 'one size' fits all approach to treatment advice did not feel helpful at one stage.*
- *Would like more help and support for* [redacted] *from school. I feel that because* [redacted] *doesn't look ill they forget he is sometimes.* [redacted] *main symptom is that he gets very tired at times which can make school difficult at times. Have in the past had to remind school why he may be tired and that it is not because of too many late nights.*
- *First diagnosis as a young teenage girl was life changing for me and the hardest thing I have ever had to experience. When I got my key for all the public toilets from NACC it was one of the best things that I could have received. I had a very rocky few years, but have realised that people are very accepting, and especially with regards to getting my own room for exams and getting the extra time made up that is wasted by me going to the toilet during it. This was my biggest fear that IBD would affect my studies, and my life. But it is so much more calming and useful knowing people are behind you and you are by yourself not disrupting other people during exams you can just relax and get on with it.*