

TAKING THE IBD STANDARDS FORWARD IN WALES

“Better Care for a Better Life with IBD”

SURVEY REPORT

**The Experience and Views of the IBD Service in Wales
from some of the People with Crohn's Disease or Ulcerative Colitis who use
the Service**

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1. Background

“Better Care for a Better Life with IBD”

Crohn’s and Colitis UK are taking a leading role in programmes to improve the quality of clinical care and implementing new approaches to the management of IBD as a long-term condition across the UK. This survey is based on those people who use the IBD Service in Wales and is closely similar to one carried out in Scotland in early 2014

2. Context - IBD Survey Wales 2014

Crohns and Colitis UK decided it would be useful and informative if a Wales 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 challenges 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 Wales 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.

We would like to thank the 447 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 Wales.

3. Methodology

The survey contains a combination of both quantitative and qualitative questions. IBD patients as well as IBD professionals were involved in the design and the trial of the questionnaire.

The survey was designed to be completed on-line (Survey Monkey) and was distributed through the Crohn’s and Colitis UK website, membership database, professionals and patient networks. 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 Wales focus those who received their IBD care outside Wales were eliminated from the survey at the first question (do you receive your treatment in Wales?). It is worth noting that some people with IBD who live in Wales receive their treatment in England

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 end of the survey.

The survey started towards the end of 2014 and was left to run until the end of February 2015. In total there were 447 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 Wales 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 Wales in terms of age, gender, and social profile.

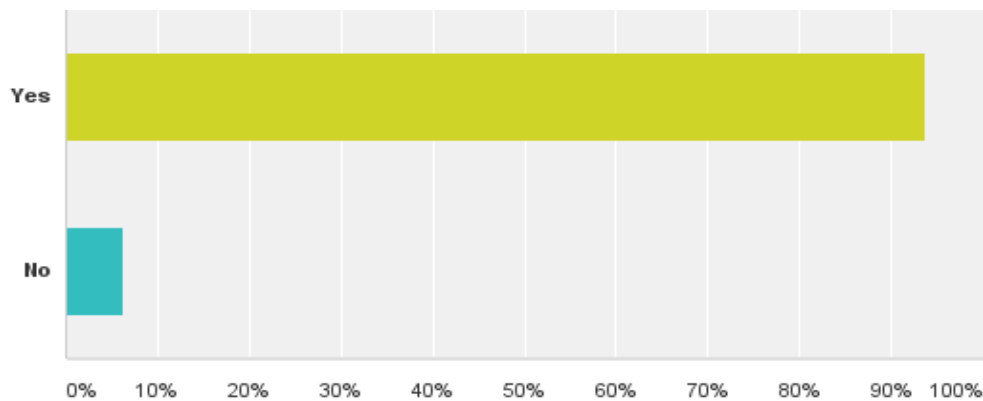
This report presents the responses to questions 1-19 which are primarily closed questions, where the respondent was asked to tick which answer most suited their circumstances

Questions 20, 21 and 22 are open ended questions and the respondent is asked to answer in free text. This gave a rich and varied response giving insight to the lives of people living with IBD in Wales.

4. Results

Q1. Do you receive your treatment in Wales?

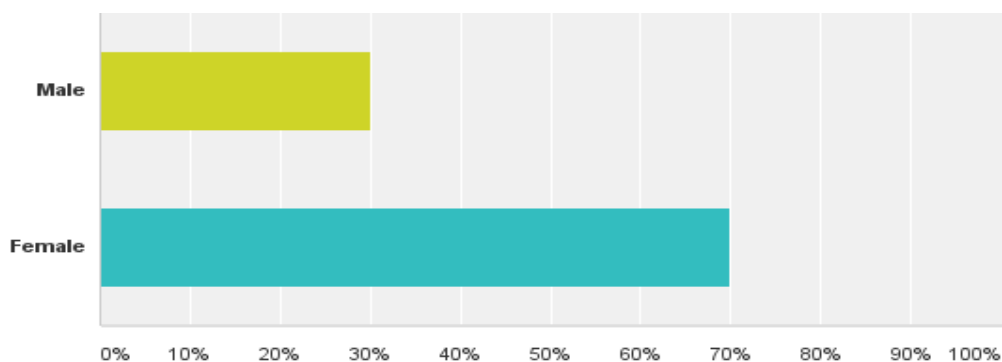
447 people answered this question.



If the answer was no then the respondent was excluded from completing any further answers to the questionnaire. In total 419 of the respondents proceeded to the next question. 28 ie 6.26% were excluded (it is possible that many of these, although living in Wales received their IBD care in England).

Q2. Are you Male/Female?

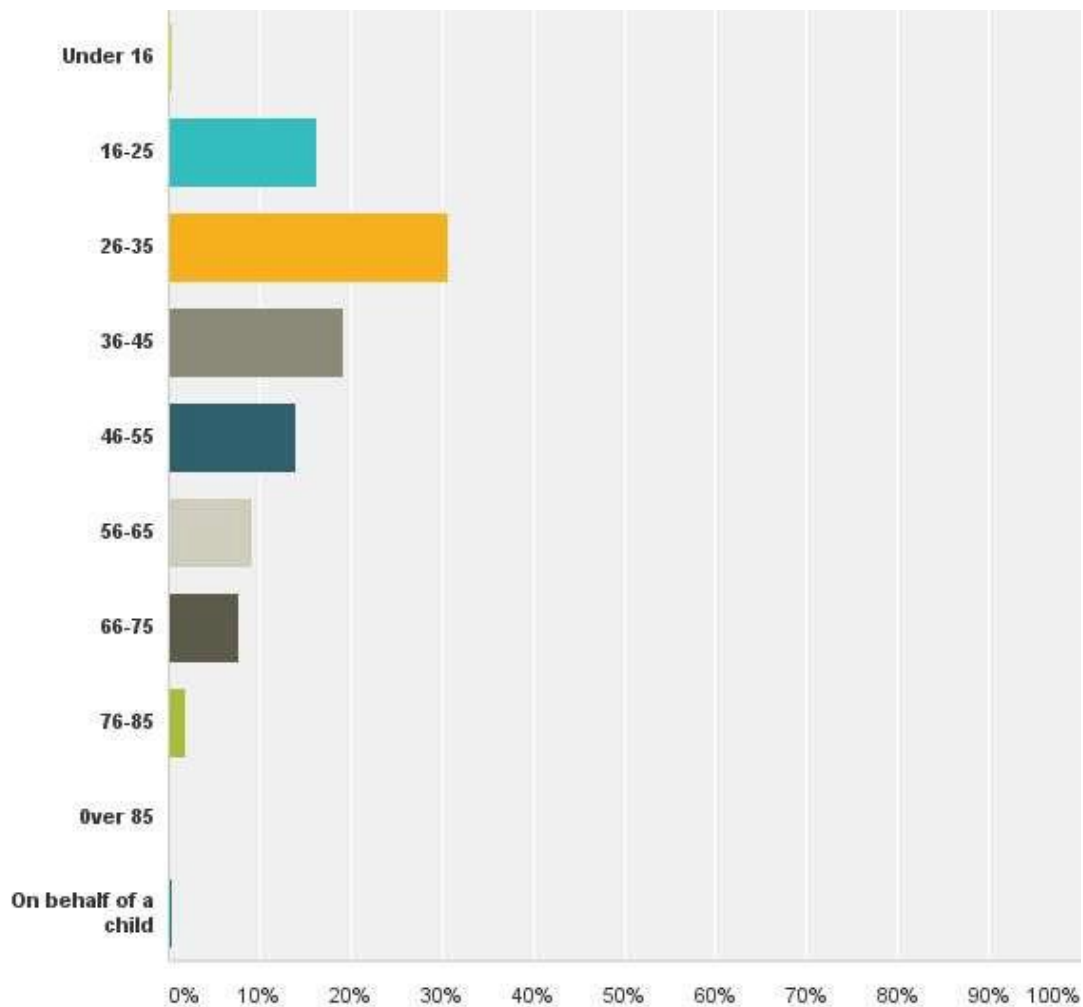
413 people answered this question.



More than twice as many of the respondents were women i.e. 69.98% women v 30.02% men

Q3. How Old Are You?

415 people answered this question



The great majority of respondents were aged 16 – 65. Whilst only 2 (0.48%) completed this said they were under 16 and a further 2 (0.48%) adults completed this on behalf of a child.

Q4. What was the year of your diagnosis?

407 people answered this question

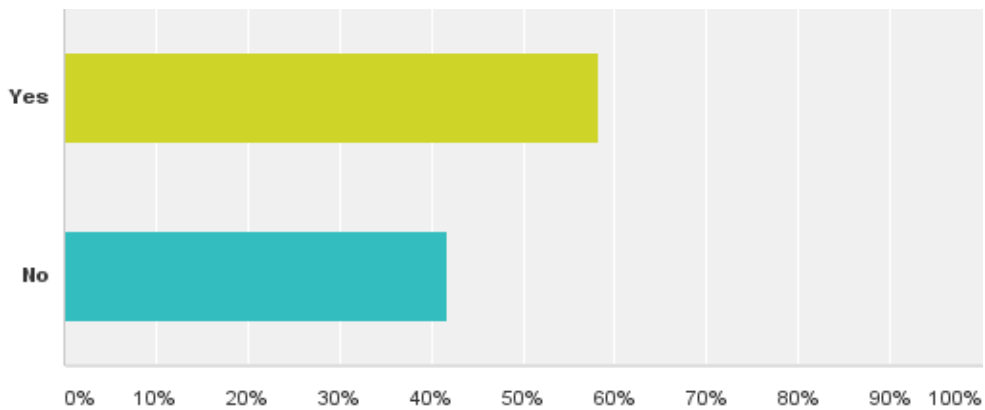
This question was solely a textual response for people to enter their date of diagnosis. Answers ranged from 1997 to 2015.

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

- *Don't remember – about 20 years ago*

Q5. Do you have an IBD Nurse (ie a nurse who is specially trained to work with patients who have Crohn's Disease or Ulcerative Colitis)?

408 people answered this question

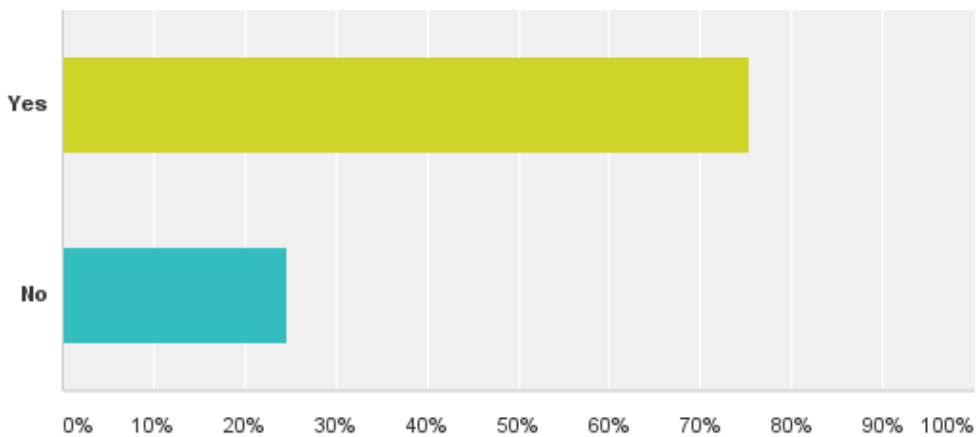


238 of the respondents to this question said that they had an IBD nurse.

- *Can contact IBD nurse at any time and she is incredibly helpful*

Q6. Do you have a regular appointment with a health care professional once a year to discuss your Crohn's Disease/Ulcerative Colitis even if you are well (annual review)

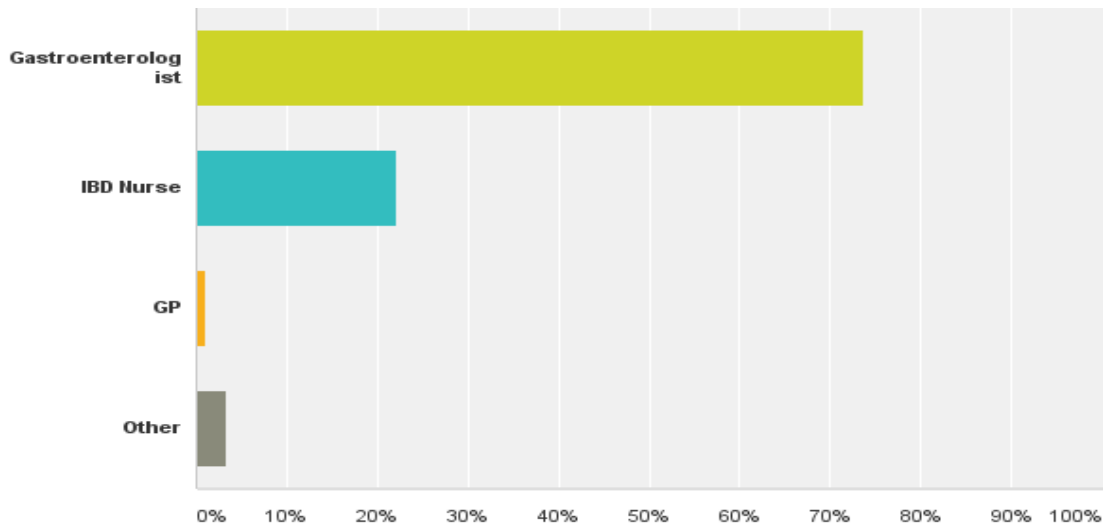
403 people answered this question



Just over three quarters of respondents reported that they had an annual review although respondents were not asked what took place at this review so it may be that they varied significantly from clinician to clinician. Regular appointments are referred to as being one of the good things about the patients' IBD service later in the survey

Q7. Who by?

303 people answered this question

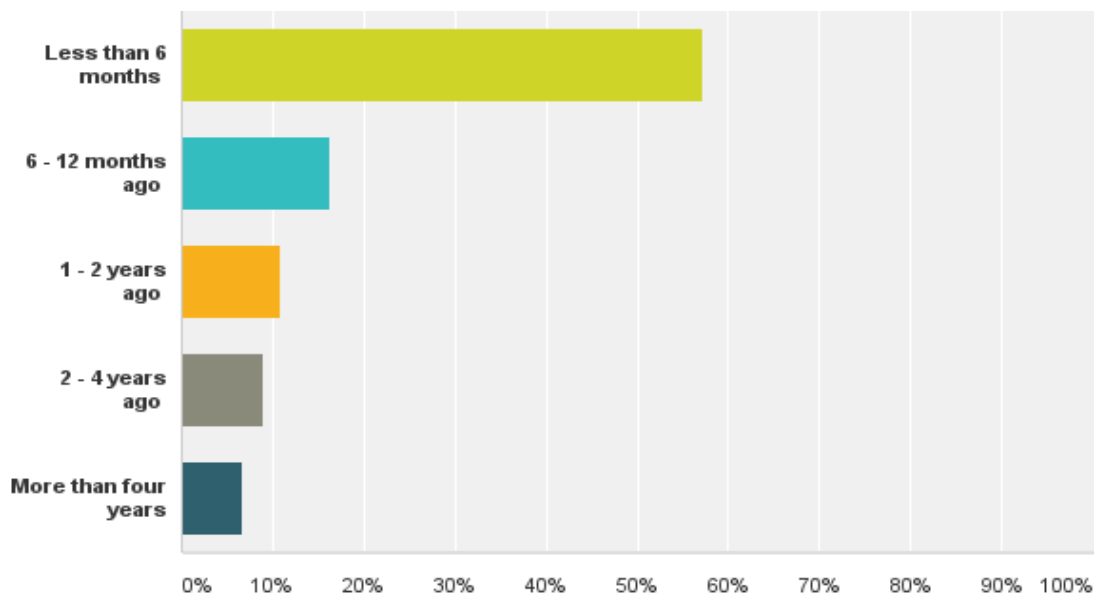


The text responses to this final cohort 'other' go on to list colorectal surgeon, bupa, consultant, gastro clinic, surgeon, and stoma nurse

- *I have 6 monthly reviews with Consultant and see the IBD nurse for treatment every 8 weeks.*
- *I've never been well long enough to go that long without an appt. I see either consultant or nurse practitioner*

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

399 people answered this question

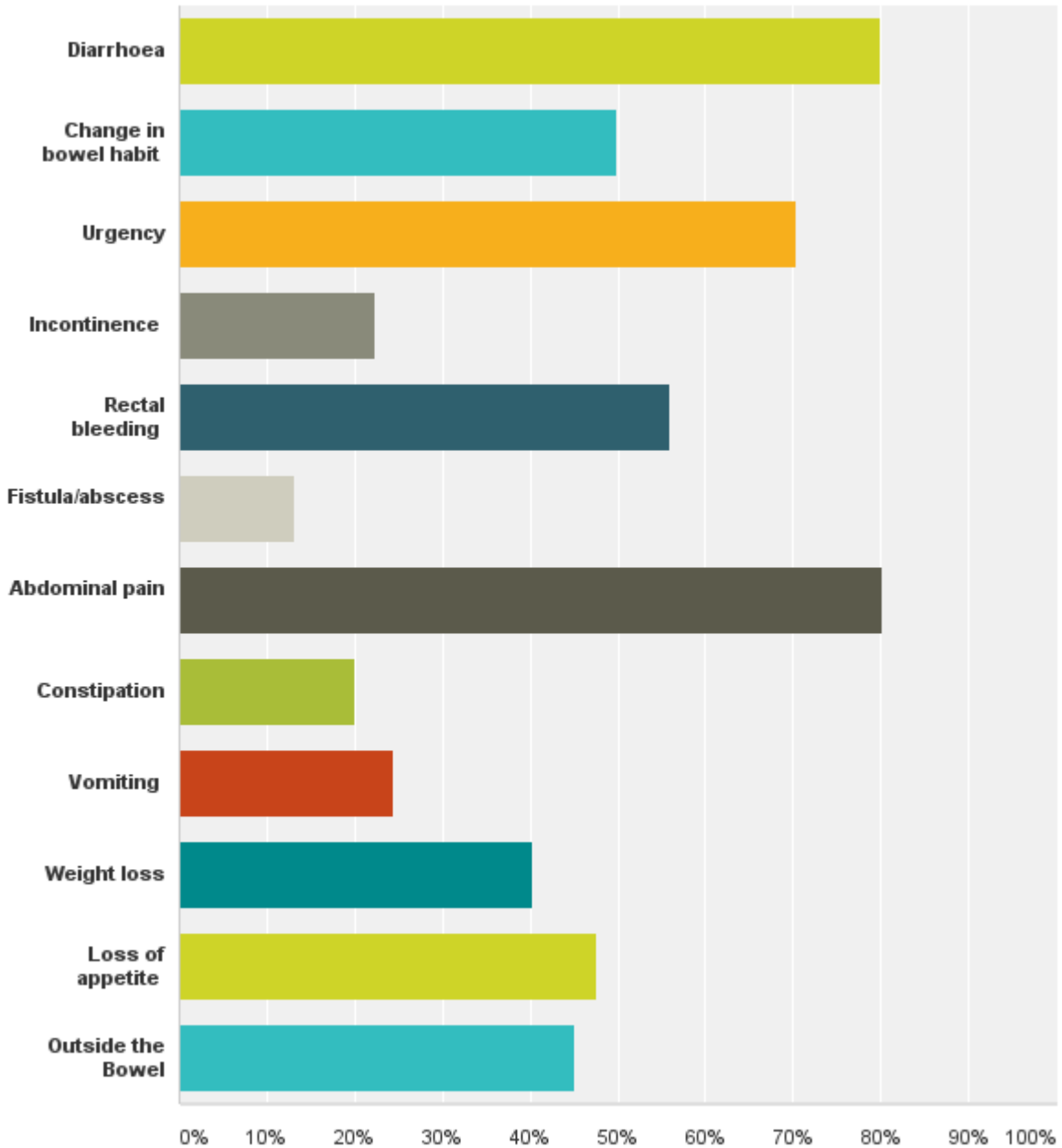


The 27 respondents who answered more than four years to this question were directed to the last three free text questions in the questionnaire. This ensured that the responses to the questions about NHS care are both recent and relevant.

Over half (57.14%) of the respondents had had a flare up in the past six months and nearly three quarters (73.43%) had had a flare up in the past twelve months.

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

370 people answered this question



A flare up of IBD can have multiple symptoms.

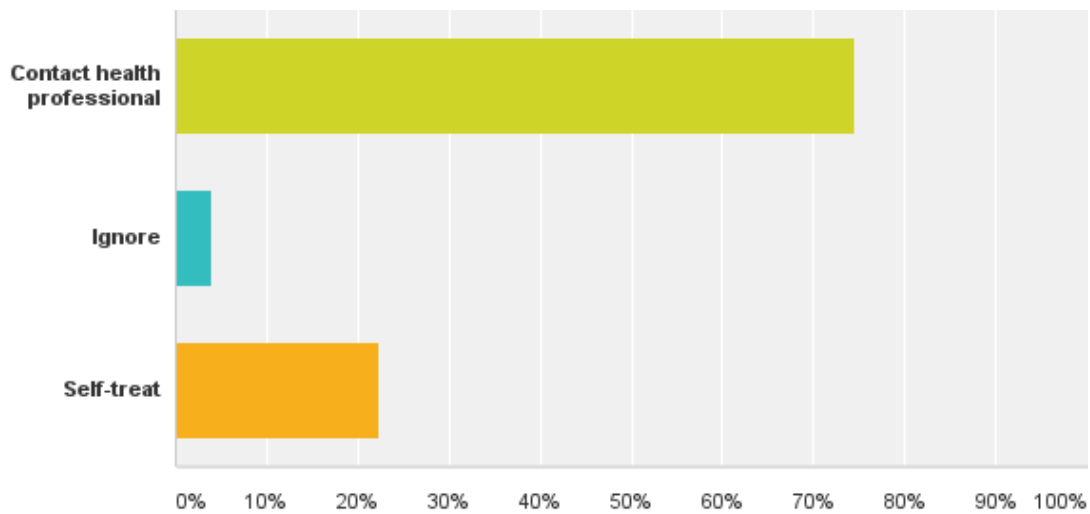
In total 2064 answers were ticked indicating that on average a flare up involved approximately 5 of the symptoms listed in the question (see graph) for each person.

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

- *nausea, fatigue, near unconscious*
- *Fatigue, depression, suicidal ideation.*

Q10. What did you do?

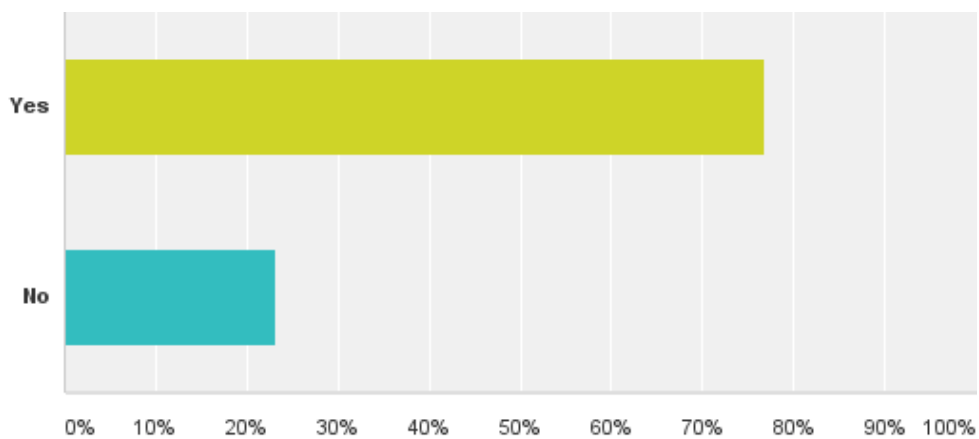
362 people answered this question



- *Partner called an ambulance*

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

82 people answered this question



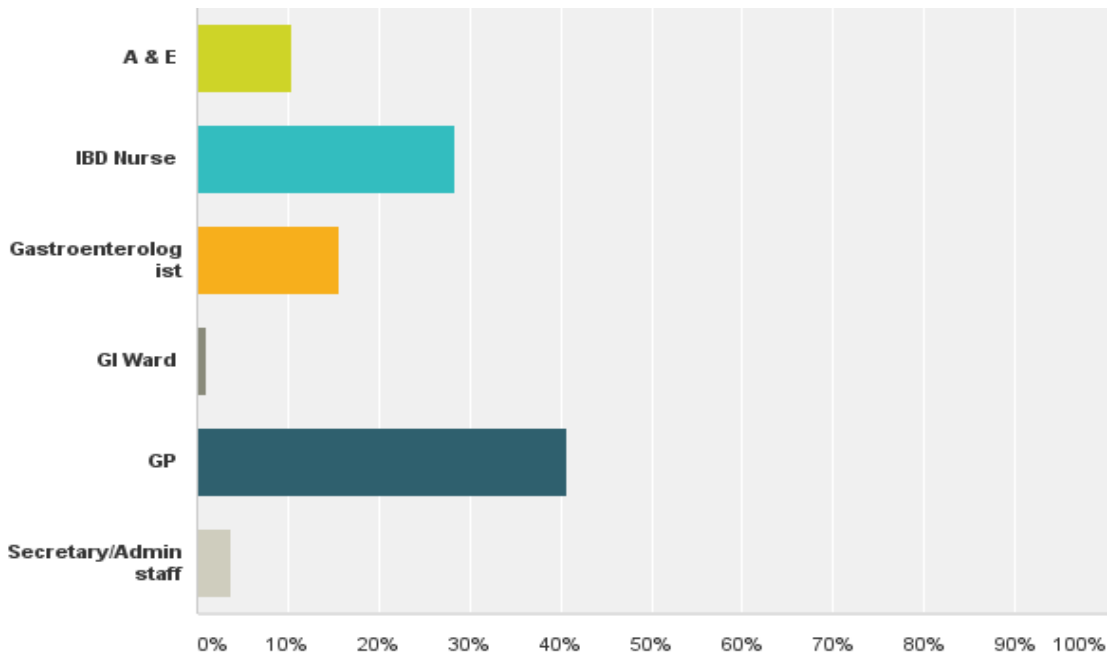
Over three quarters (76.83%) of these followed self-treatment guidelines previously agreed with a health professional

19 (23.17%) respondents said they did not follow guidance.

- *I have not been told what to do during a flare up.*
- *I have been given no guidelines*

Q12. Who did you contact?

268 people answered this question

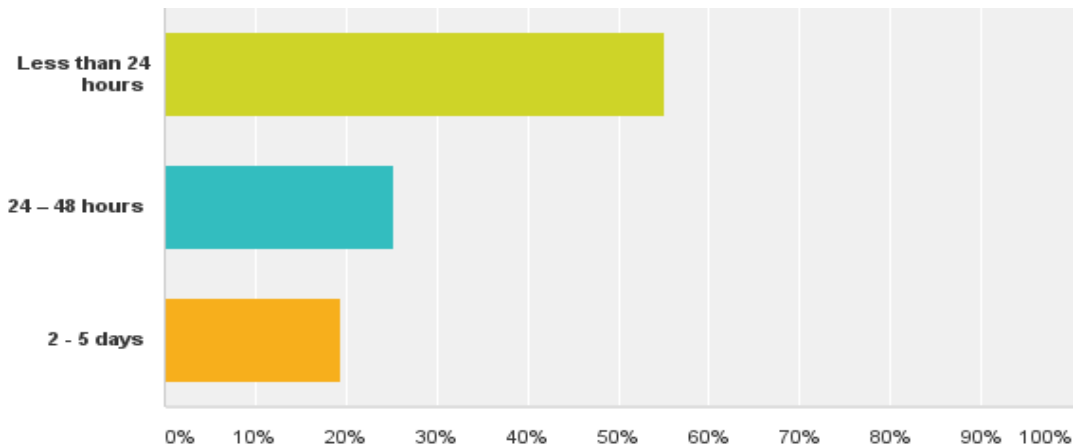


Other included:-

- *Stoma nurse and GP*
- *IBD pharmacist*

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

241 answered this question



The majority of respondents 55.19% who answered this question (total 241) waited less than 24 hours for advice which means that in total just under 45% waited more than 24 hours and up to 5 days.

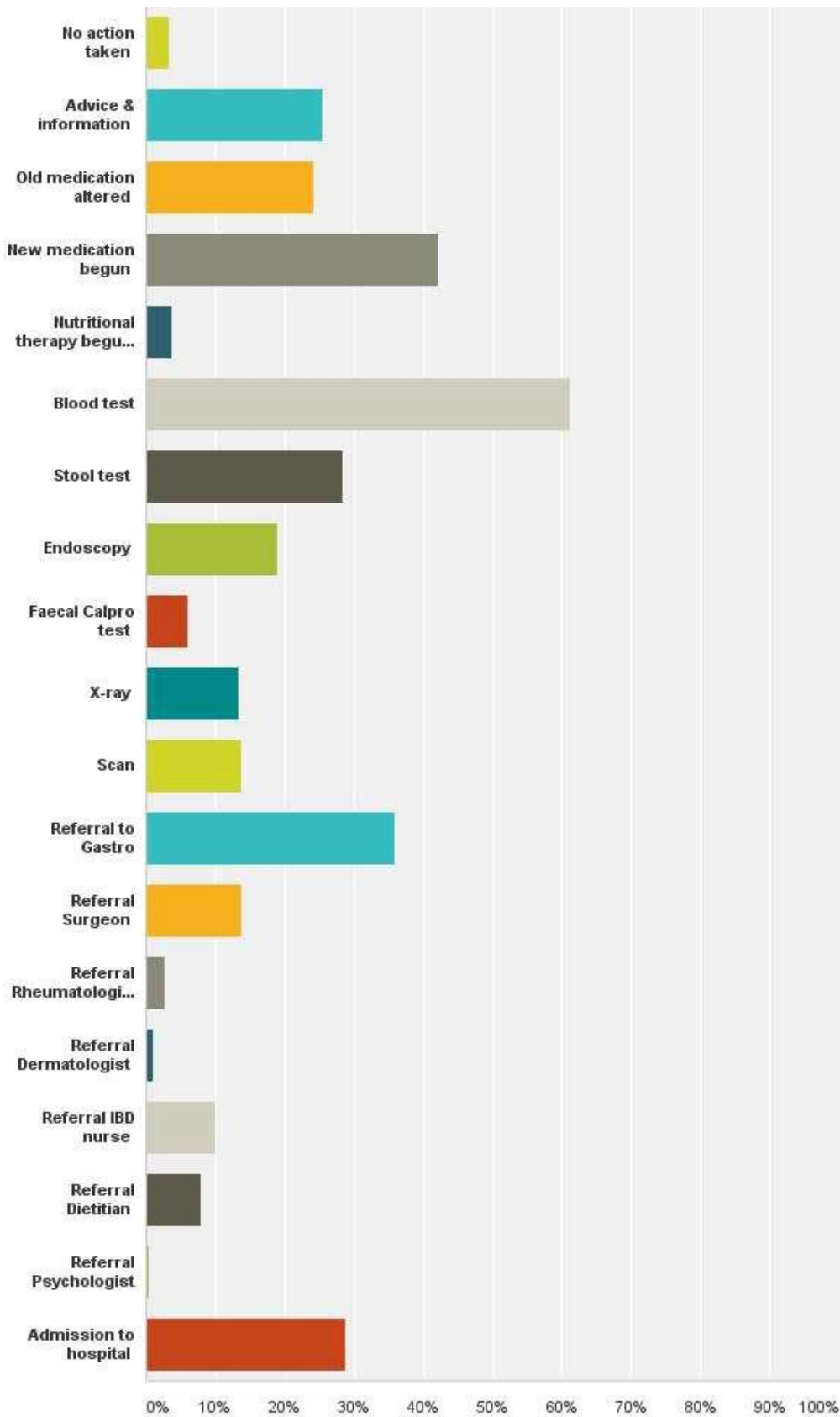
However 32 people skipped this question and went on to answer the following question –

More than 5 days please state and responses included:-

- *Weeks*
- *Just over two months*
- *2 - 3 weeks*
- *Still waiting 3 months later*

Q14. What action was taken? Please tick as many answers as appropriate.

268 people answered this question



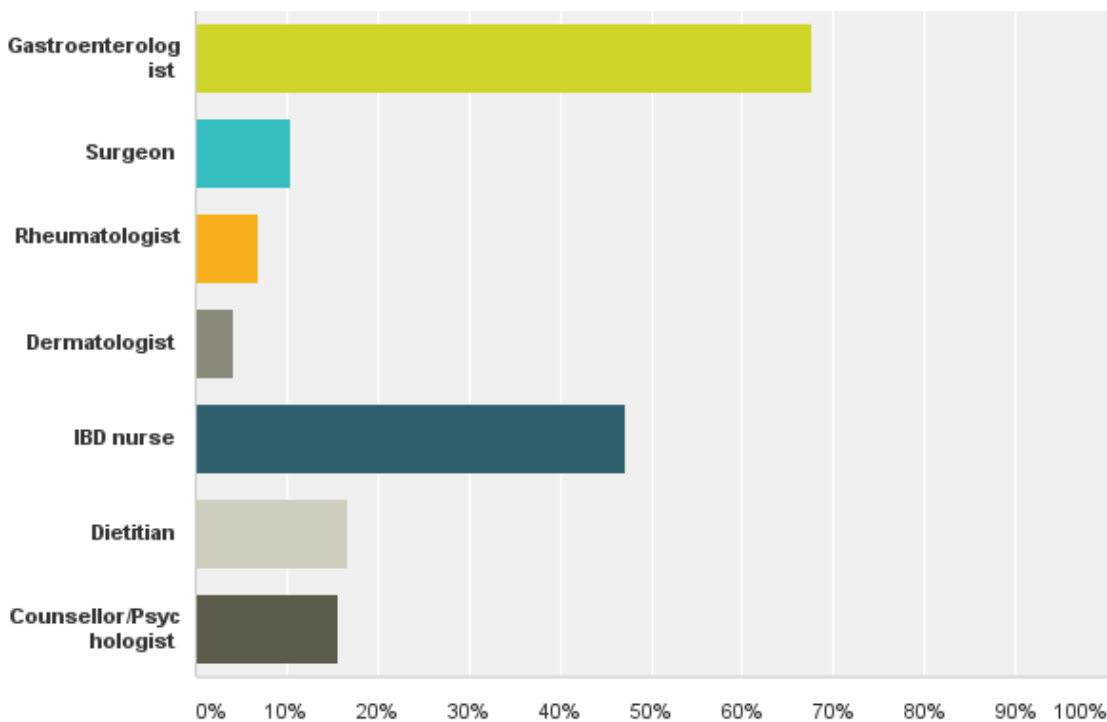
The graph on the previous page shows the overall results to this question. Only 10% were referred to their IBD nurse (just marginally more than to their dietitian at 7.84%). The most common referral was to their gastroenterologist (35.82%) The most common action taken was blood test (61.19%) followed by new medication (42.16%)

Other responses not included in the list of options included:-

- *Steroidal therapy started*
- *Iron transfusion*
- *Waited 3 days for a telephone call from GP, missed call as it was at 7pm on a Friday to be told that as it was a weekend nothing could be done and if I still needed advice to call the surgery again on Monday. I intend to go into surgery on Monday (as this flare up is happening right now) and get an emergency appt with any GP I can see*
- *Due to lack of advice I self-medicated and increased my steroids. Luckily I had some spare.*
- *Gynaecologist - dismissed my symptoms after 6 days.*

Q15. Would you have liked to have been referred to (please tick as many answers as appropriate):-

191 answered this question

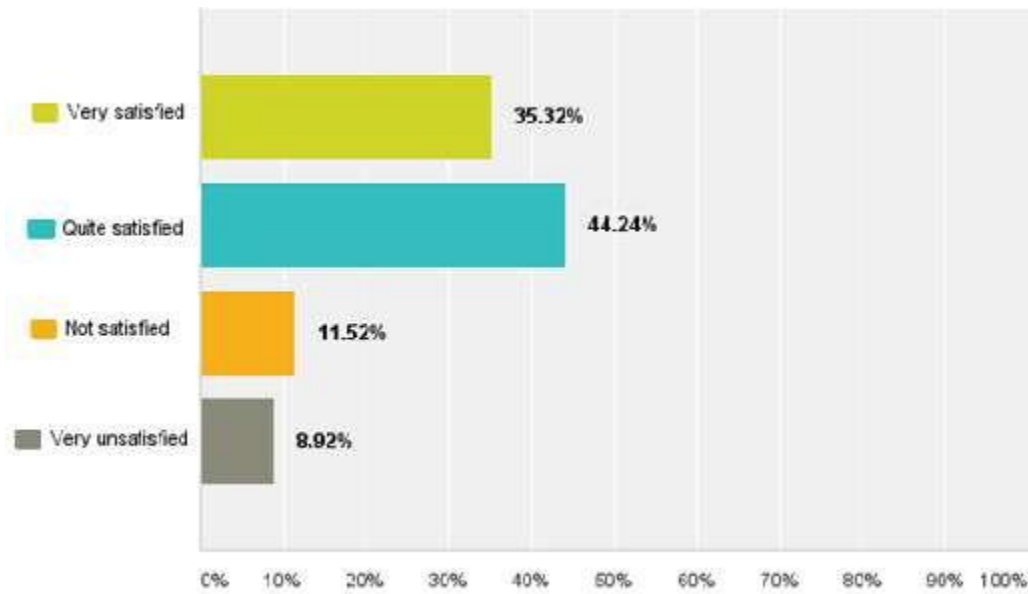


One respondent replied:

- *None, my IBD Nurse gave me the correct treatment and my flare up stopped within 24 - 48 hours*

Q16. Overall how satisfied were you with your treatment?

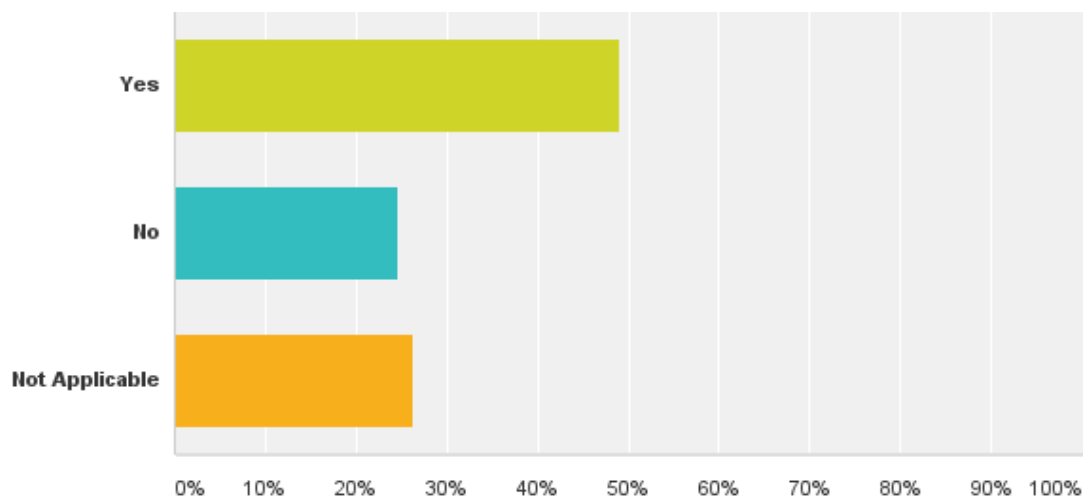
269 people answered this question



214 (Just under 80%) reported being either *very satisfied* or *quite satisfied* with their treatment. This leaves 55 people (20%) who were *not satisfied* or *very unsatisfied*.

Q17. During this flare did you take time off work?

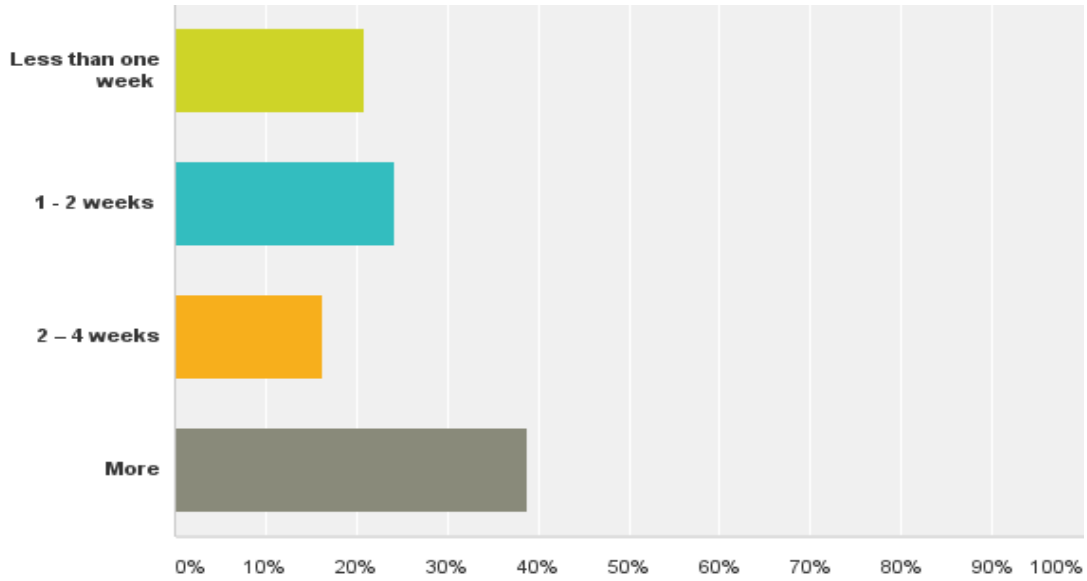
361 people answered this question



Just under 50% of respondents had taken time off work during their recent flare

Q18. How Long?

178 people answered this question

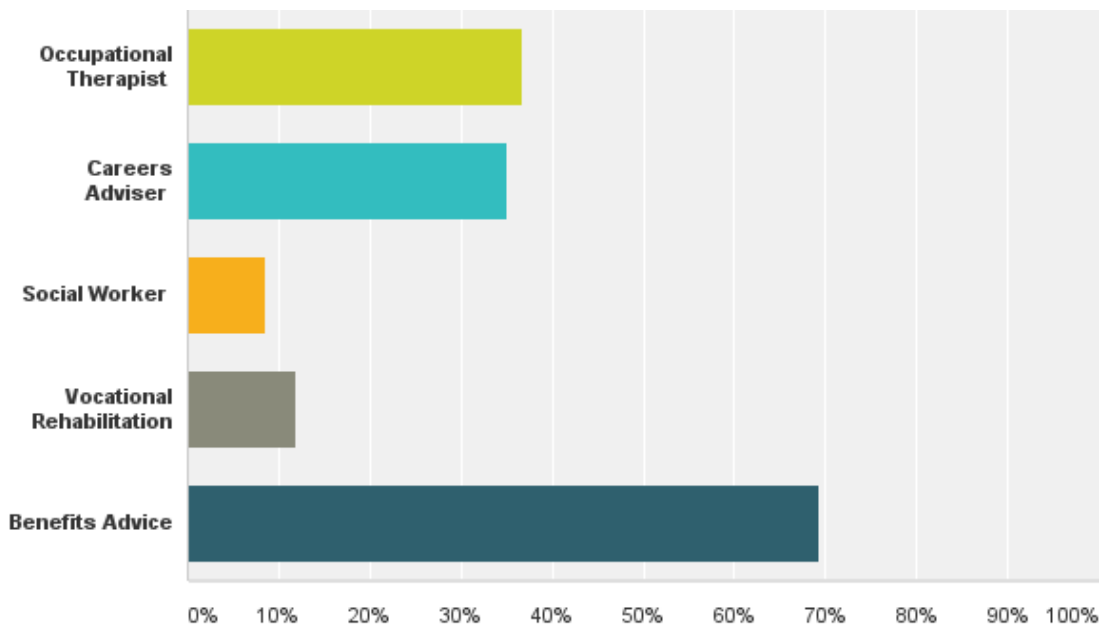


The text responses to this question vary enormously. One person stated that they had:

- 6 months, 3 operations
- I lost my job as a contractor after requesting a third week off (all unpaid). I have not worked since.
- I have been on the sick for 6 months

Q19 Would you like a referral to any of the following (Please tick as many answers as appropriate)

117 people answered this question



Just under 70% of those who responded to this question would have liked some Benefits Advice

Free text questions

The last three questions in the survey are free text questions. These answers include responses from those who had not had a flare up in the past four years and had subsequently been excluded from filling in the responses about their NHS Care as it was not regarded as having been recent enough to be relevant for this particular survey.

The respondent was invited to :

Q20. Tell us two things which are good about your NHS care (314 responses) Most frequent words used (in order)

- IBD Nurse
- Consultant
- Care
- Hospital
- Appointments

Q21. Tell us two things which would improve your NHS care (304 responses)

Most frequent words used (in order)

- Appointments
- Waiting
- IBD Nurse
- Hospital
- Care

Q22. Anything you would like to tell us about living with IBD (202 responses)

Most frequent words used (in order)

- Life
- IBD
- Understand
- Flares
- Living
- Fatigue/Tiredness

This qualitative data is rich with the experiences of people with IBD and living in Wales, both of the experiences of health care and daily living.

- *It's life changing, I have no social life, I'm tired all the time it stopped me from doing things I loved doing and now I'm really depressed having ileostomy. I wish I didn't have to go out anywhere or see any people, until you have it yourself you won't be able to fully understand. I work on gastro ward and we had many patients with Crohn's, all I knew and thought about Crohn's was that people go to the toilet more often and have some stomach cramp and now I know there is so much more to it...horrible illness.*
- *Fatigue is a debilitating factor with IBD. It's shrugged off as 'well it's what you should expect with IBD' I understand that but help to overcome this to enable you to work is required. I'm lucky I can work from home but if I didn't I couldn't manage my job.*
- *No one talks about the other effects of living with IBD, ie. travel anxiety. It should be a recognised disability.*

- *It totally dominates my life and as soon as I step outside my front door, I am in a constant state of anxiety that I will soil myself. It not only restricts where I go and what I can do. Even then, when shopping, the amount of businesses that refuse access to their toilet despite informing them of my plight is disheartening and ultimately soil myself as a result. In the winter that's easier to hide (long coat) but in the summer, it's a nightmare. It's a really nasty, insidious disease.*

See **Appendix 2** for a few more of the comments as examples of the responses received:-

5. Conclusions

The purpose of this survey was:-

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

The topline results from this survey were presented by Crohn`s and Colitis UK at The National IBD Audit Meeting in Cardiff in March 2015 to an audience of patients, clinicians, nurses and Dept of Health and Social Care officials.

Crohn`s and Colitis UK continue to refer to the findings in this survey in its work with the Dept of Health & Social Care, AM`s, patients and clinicians to further develop IBD Services in Wales.

Some topline results:-

- With just over 400 responses it would be difficult to draw any hard and fast conclusion on any topic, and the results of any cross tabulation on a reduced cohort of these respondents would be statistically of dubious value. However the following figures are interesting indicators:-
 - More than half (almost 60%) of the respondents said they had an IBD nurse.
 - Just over three quarters (75.43%) of respondents reported that they had an annual review (24.57% do not).
 - Almost three quarters (73.6%) of those that have an annual review, report that this is undertaken by their gastroenterologist and 22.11% report that it is undertaken by an IBD nurse
 - Over half of the respondents (57.14%) report a flare up within the past six months.
 - A further 16.29% more in the last 12 months i.e. almost three quarters of respondents had a flare in this period.
 - Just under 75% contacted a health professional during this flare (The most popular first contact was their GP [40%] and 10% went to A&E.
 - 55.19% reported waiting less than 24 hours for advice after contacting their health service, but the remainder waited between 24 hours and 5 days.
 - 28.73% said they were admitted to hospital during their last flare.
 - Over 20% reported being “not satisfied” or “very unsatisfied” with their treatment for their recent flare.

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 Wales, particularly their views and experiences of their NHS provision.

Peter Canham; Patient Involvement Adviser; Crohn`s and Colitis UK June 2015

Appendix 1

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

314 people answered this question, comments varied but the theme of good consultant, accessible IBD nurses and free prescriptions recur regularly right across the board.

- See IBD nurse often. Do not pay for prescriptions.
- I have access to an excellent consultant & surgeon. The hospital I attend is only 30 minutes drive away.
- A good listening consultant. Regular colonoscopy.
- Free prescriptions. Very dedicated staff.
- Great to have an IBD nurse when you get hold of them. GP has no clue how to help.
- Great consultant and a fantastic team of nurses.
- Regular appointments, good access to specialist nurses, access to research programmes for new medications.
- Fast treatment when having a flare up. Lots of checks i.e blood tests, scans.
- Prompt response from my IBD team as I have very complex Crohn's disease. All surgeries have been prompt and executed superbly by all involved and aftercare has been excellent.
- Good regular check ups and constant monitoring
- Able to get an appointment at the Hospital to see the consultant within 48 hours.
- Free medication.
- Communication advice.
- I know my consultant and three IBD nurses very well now and I like the continual contact with the same individuals. They have reacted well when I have urgently needed their help and I have their direct dial telephone number.
- Consultant and IBD nurse and dietitian are excellent.
- Can contact IBD nurse at any time and she is incredibly helpful.
- My IBD Nurse has been a rock for me, always there when I need her. She started the same week I was diagnosed so has literally been there since the start. The fact my treatment and on-going medication are free.
- That I can phone my nurse whenever I need to discuss something, they are a very close team and make me feel a part of it with regards to my treatment.
- Ability to contact health professional with any questions (ie IBD Nurse) is very easy and quickly responded to usually within 24 hours, but normally same day. Can talk openly about treatment with consultant and discuss my views on what works/to try next...ie I made the decision to increase azathioprine rather than increase infliximab infusions.
- Very knowledgeable IBD nurses. Very kind and caring.
- Shared care policy; as I take azathioprine, I need regular blood tests. Under the shared care, I am able to have these at my local GP surgery as opposed to having to travel to hospital. IBD Helpline; although not very quick in responding (sometimes unattended for 3 days in a row) it is useful to be able to contact specialist support in situations where a GP would not be able to assist.

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

304 people answered this question and the responses were very largely the reverse of the answers to the previous question i.e. long waits for diagnosis, difficulty in accessing clinicians, cancelled appointments, long waiting times and getting repeat prescriptions.

- I feel an IBD nurse would help many of my fellow local sufferers as there isn't one in my local hospital.

- *Waiting time and GPs should be more aware of IBD - I've been going to GPs for over 4 years with the same worsening symptoms, but all they were giving me were gaviscon or peppermint tablets, nobody was sending me to see any specialist just telling me I've got IBS (so easy to say cause there is no test for IBS) I felt I was being ignored. I only got diagnosed because I became very poorly, vomiting after every meal, lost lots of weight and pain was so bad that I had to take days off work, my boss called me in to talk about my sickness and luckily for me I work on gastro ward she thought it might be something else than IBS so she spoke to our gastroenterologist consultant and within a week of seeing her I've been diagnosed with Crohn's. Unfortunately it got so bad I had to have surgery - first small bowel resection then ileostomy and then I had a leak so had to have another op, all within 3 months time. I feel like if I hadn't been ignored by my GPs for all these years maybe I wouldn't have to have all these surgeries, maybe biological treatment would have helped me, that's why I feel GPs should be more aware of Crohn's disease especially with young people who are being ignored and everything is being put down to IBS.*
- *Appointments are often cancelled with the need to rearrange, once I had 3 appointments cancelled in a row.*
- *Can't get an appointment as clinics are too full. When you are having a flare up you can't wait 48 hours to speak to an IBD nurse, you want help NOW*
- *Toilets per room, not 2 toilets to a ward.*
- *Availability of my IBD nurse. She is flat out busy and at times it has been hard to discuss things. Better quality of food when admitted. Dietitians prompting good eating, but the food available is pretty terrible, it doesn't help the situation at all.*
- *As I work full time difficult to get suitable doctor's appointments. Repeat prescriptions take many visits to the doctors.*
- *IBD nurse or helpline.*
- *The ability to bypass A&E when you have a flare up. A&E just want to get you out of their department as soon as possible without assisting you to get specialist referral.*
- *GPs need better training in diagnosing IBD. It took over two years to be diagnosed and by then I was very ill.*
- *I have been waiting for scan colonoscopy since May 2014*
- *Access to a services/health care that deal with all aspects of living with Crohn's eg I only recently discovered there is a continence clinic from a dog walker despite my GP, IBD nurses, stoma nurses and Consultant all being informed. I experience daily accidents and struggled with money to purchase continence pads. As previously mentioned, access to relevant psychological support, particularly when facing body changing surgery. Better understanding of the full and wider impact Crohn's can have on sufferers and quicker referrals to those relevant specialists eg dermatologist and urologist.*
- *I feel a bit fobbed off with my GP I recently moved to Wakes and he asked if I could go back to my original consultant! Which is 6 hours away! I said no and was referred to Aberyswith and not heard anything and it's been a month!*
- *The procedure for ordering ostomy supplies is more complicated in Wales than in England. I need to order a prescription and have that sent to the supplier and then the supplies are sent to by pharmacy. It would be better to simply order direct and have them delivered direct like in England. There needs to be a greater understanding of the secondary factors associated with IBD, especially psychological.*
- *To be seen by gastroenterologist rather than general surgeon, referred to general surgeon as "quicker".*
- *Access to IBD nurse.*
- *No cover is provided when my IBD nurse is away or on leave, so during these times it is difficult to access specialist advice about my UC and the GP is a last port of call and often doesn't know what to do. I rarely get to see my consultant in clinic. I last saw my consultant in clinic in July 2013.*

- *Should have annual checks on condition.*
- *Having an annual review Being able to see the same doctor at my surgery instead of a different one every time.*
- *An IBD nurse available in the area and more advice on pain management.*
- *Not having to go through the process of A +E and going straight to a ward if needed.*
- *My GP isn't confident in treating a Crohn's flare - he was reluctant to prescribe steroids.*
- *Waiting time to see gastroenterologist.*
- *Feel very isolated. Have had stomach problems for 35 years, but only recently diagnosed with Crohns. The delay has surely impacted on my health and wellbeing.*
- *I requested the advice of a dietitian because I was worried about my weight loss, but it has taken me a year to get referred. I've now cancelled as I've managed things myself in this time. So I guess the first thing would be to get the care I needed when I need it. An IBD nurse would help to provide assistance when hospital treatment might not be necessary.*
- *Help to improve fatigue.*

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

202 people answered this question the theme of isolation, embarrassment, information, wider awareness and access to public toilets recur.

- *Anaemia and fatigue are hard to live with sometimes.*
- *It's life changing, I have no social life, I'm tired all the time, it stopped me from doing things I loved doing, and now I'm really depressed having ileostomy, I wish I didn't have to go out anywhere or see any people, until you have it yourself you won't be able to fully understand. I work on gastro ward and we had many patients with Crohns, all I knew and thought about Crohns was that people go to the toilet more often and have some stomach cramp and now I know there is so much more to it...horrible illness*
- *On your own. Depression. Feeling ill. Nobody understands the illness.*
- *Fatigue is a debilitating factor with IBD. It's shrugged off as 'well it's what you should expect with IBD'. I understand that but help to overcome this to enable you to work is required. I'm lucky I can work from home but if I didn't I couldn't manage my job. Some of us are conscientious and want to do our best. We need help to do that !!*
- *Dignity is important, consultant didn't seem to grasp that 23 year old female (at time of diagnosis) may need some privacy and time before/after examinations*
- *Benefits advice.*
- *No one talks about the other effects of living with IBD, ie. travel anxiety. It should be a recognised disability.*
- *it's a horrible thing which changes your whole life. Somewhere to talk to - nurse or a group when others ie family don't know what you are going through.*
- *t's a physical & mental battle every single day.*
- *It totally dominates my life and as soon as I step outside my front door, I am in a constant state of anxiety that I will soil myself. It not only restricts where I go and what I can do. Even then, when shopping, the amount of businesses that refuse access to their toilet despite informing them of my plight is disheartening and ultimately I soil myself as a result. In the winter that's easier to hide (long coat) but in the summer, it's a nightmare. It's a really nasty, insidious disease. There is a distinct lack of awareness about IBD in the community. Diseases and conditions like diabetes, cancer, hypertension dominate the media to such an extent that other conditions like Crohn's or Cystic Fibrosis are almost completely ignored.*

- *It is debilitating and embarrassing. I now have a stoma, which was suppose to give me back some of my life. It has done the opposite, I hate going out because of leaks and have become practically a shut in. I hate this illness, and the people who don't understand and compare it IBS. Give me IBS over IBD any day.*
- *If you have UC it's just much easier to have an ileostomy than having to live with the pain of UC.*
- *There needs to be greater awareness, especially among local councils about the need to keep public toilets clean and accessible for people with chronic health conditions such as IBD.*
- *Living with IBD is not easy, and at times is utter hell, but I have learnt over the years to listen to my body in order to recognise symptoms, changes and warning signs etc. Since my diagnosis 13 years ago, a lot has changed. I was originally told that diet had no impact on IBD. However my diet has drastically changed by my own experimentation with different food types to see what is and isnt tolerable. My list of tolerable foods has severely decreased over the last 12 months, but I know what I need to keep my body fuelled and what my body can take. Sometimes having to use nutritional therapy to top up my essentials during a particularly bad week of symptoms, but not actually a flare bad enough for steroids. I have also tried numerous medications which all failed to keep me in remission and am now on immunosuppresant tablets and biologic injections, with the use of steroids and nutritional therapy during a flare up. Having a positive attitude helps, I am aware of the fact that 'When I am well, I am well and do what I can, living life to the fullest, and when I am flaring, life, I'm afraid, has to pause'. Being as fit and healthy as possible is also an added bonus, even if it's just a little short walk around the garden. I love to run and do so as much as possible when I am well enough. IBD is a very individual disease and each sufferer will get different symptoms and reactions and deal with it differently.*
- *When I was first diagnosed, I was either ill and in hopsital or well with no symptoms at all. Nowadays I have more every day symptoms, my diet is very restricted, I have chronic fatigue and when I do flare take a lot longer to recover. There is always something new this disease can throw at me and I am never surprised by a new symptom that may occur, but accept it as part of my disease. I find peoples attitudes to the disease one of the harder aspects, I try and educate them to what it is and how people suffer. I cannot even count the amount of times I am told 'But you don't look ill' or 'I wish I was a skinny as you' etc, etc. Its all down to ignorance and a lack of knowledge, its not anyones fault. I had no idea what IBD was before I was diagnosed, I had heard of it but didn't realise the effect and implications it would have on my life. Having the internet and more knowledge at my fingertips is very helpful, although I am very aware that not all that you read is correct. This does worry me about newly diagnosed sufferers as IBD has been in the media a lot lately and yet the information provided is still incorrect, this is where Crohn's and Colitis UK comes in. It provides up to date relevant information, support and reading material that all sufferers need to help tackle IBD face on. It's a shame that I have never ever seen a poster/flyer or advert for Crohn's and Colitis UK or any other support group in my local hospitals or GP surgery and only found out about it through a friend of a friend. One day, funding permitting, an introduction pack for all newly diagnosed patients would be extremely beneficial. Since my surgery in 2012 my health has improved signficantly, however, my two sons aged 23 and 15 years have been diagnosed within the last year, the youngest having just undergone surgery also. Prior to surgery I was unable to make plans as my Crohn's would flare up unexpectedly, often resulting in me being admitted to A and E at the local hospital.*
- *Embarrassment*
- *Fatigue is one of the worst symptoms for me.*

- *Crohns affects every aspect of my life as is extremely hard to live with, especially as mine has been active for over 20 years with no remission. Medical help is good, but this only addresses the psychological aspect to a limited extent. I need to work fulltime to support myself, as I am unable to claim any benefits and the stress of this only exacerbates an already uncontrolled condition.*
- *Very isolated and alone during flare up - currently single - cannot imagine dating someone with this disease. Appalled at the waiting times to see a consultant especially as bowel cancer runs in my family.*
- *When in flare-up mode I'm unable to leave my home for any length of time.*

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