

Community Action on Health

“I feel as if I’m constantly fighting with myself”

Patient Experience of Inflammatory Bowel Disease

April 2011

A report for Blue River Consulting



Community Action on Health is a charity working within Newcastle to tackle health inequalities through patient, carer and public involvement.

We have vast experience and expertise in gathering the views and opinions of patients, carers and the general public in relation to health services. For example:

- locating new GP surgeries
- services to include in new community health facilities
- visibility of existing health services
- changes to care pathways

We employ various quantitative and qualitative data collection techniques:

- Questionnaires – paper-based and online
- Participatory appraisals
- Drop-in events
- Face-to-face interviews
- Focus groups
- Informal group discussions

We also provide guidance on:

- how services can engage with patients, carers and the public
- developing patient-friendly services
- a patient-focussed approach to delivering health services

For more information about the services we can provide please contact Nick Forbes on 0191 2263450 or email nick@caoh.org.uk. Visit our website at: www.caoh.org.uk

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Section 1: Introduction

1.0 Introduction

1.1 The project and its aims

Community Action on Health (CAOH) is an independent charity working within Newcastle to tackle health inequalities through patient, carer and public involvement.

Blue River Consulting Ltd has commissioned Community Action on Health to carry out research into patients' experience of Inflammatory Bowel Disease (IBD), in order to inform commissioning and treatment decisions in and beyond the North East.

Blue River will also use the research findings to develop a commissioning toolkit to be used as a training resource for GP consortia.

1.2 Objectives

The key objectives of the project are to:

- Map patient experience of early symptoms and diagnosis of IBD
- Explore patients' experience of treatment and medication
- Assess perceptions of outpatient care as well as inpatient hospitalisation
- Examine patients' views on priorities for treatment and identify common themes
- Identify patients' measures of quality of life, and in particular to explore patient priorities in terms of symptoms that most affect their quality of life
- Analyse patients' views on the relative importance of clinician-controlled treatment and individual responsibility for self-management

1.3 Inflammatory Bowel Disease

Inflammatory Bowel Disease and its commonest conditions may not be as widespread or widely recognised as some other chronic diseases, but research by the national support group Crohn's and Colitis UK estimates that IBD affects one person in every 250 in the UK. Between 9,000 and 18,000 new cases are diagnosed each year and while numbers appear to have stabilised recently, new cases of Crohn's in particular rose steadily among young people over the last few years.

The symptoms of both conditions vary from patient to patient in terms of type, frequency and severity. However, common themes do emerge and whatever its individual manifestations, IBD tends to have a dramatic detrimental impact on patients' lives.

This paper examines the experiences of 27 sufferers in Tyne & Wear, Northumberland and County Durham, most of whom were identified by local Crohn's and Colitis UK support groups or invited to participate by Dr John Mansfield, Consultant Gastroenterologist at the Royal Victoria Infirmary

Section 2 - Methodology

2.0 Methodology

In order to meet the objectives of the project, Community Action on Health used a number of distinct and complementary qualitative techniques.

2.1 Qualitative techniques

Given the range and varying severity of IBD symptoms, the impact of the condition on different aspects of patients' lives and the ultimate aim of this research, Community Action on Health chose to adopt a predominantly qualitative approach to the project. We wanted to ensure that our research gave participants the opportunity to describe their experiences and, between them, identify common priorities that can inform future commissioning and treatment approaches.

We therefore established a programme of qualitative research, which is primarily concerned with gaining an understanding of how people feel about their experiences and which therefore fitted with the overall objectives of this project.

- 2.1.1 We invited 37 people to participate in a focus group, in the hope of recruiting up to 10 attendees. Focus groups, which work best with a cohort of up to 10 people, are commonly associated with collecting qualitative and interactively generated information and in this case we gathered extremely valuable insights from the seven people who were able to attend on the day.

One of the most striking outcomes of our search for participants in every aspect of the research was people's enthusiasm for taking part – the vast majority of the people we invited were more than willing to join the focus group, but many were prevented from doing so by their IBD symptoms and the restrictions these place on their daily lives.

In addition to those who were unable from the outset to make the necessary arrangements to attend, three people who had signed up to take part in the focus group were obliged to cancel on the day because of flare ups and other condition-related complications.

- 2.1.2 However, three other people who were unable to attend the focus group agreed to be interviewed by telephone.

- 2.1.3 While we considered a focus group approach to be particularly appropriate for this project, it was also important to gather information from as large a cohort as possible, in order to identify patterns and apportion appropriate weight to the information we gathered.

To this end we developed a questionnaire, addressing the same issues as the focus group questions, which 17 people completed and returned to us by post. Again, the fact that such a high proportion of the 26 people who asked for and received questionnaires completed and returned them within the project timescale reflects the

strong commitment of IBD sufferers to sharing information that might lead to better understanding and treatment of their condition.

2.2 Participants

2.2.1 All participants

The Durham and Wearside Crohn's and Colitis Support Group provided invaluable support to this project, by mailing participation requests to 75 selected members, at least 12 of whom contributed to the research in one way or another (not all questionnaire respondents answered the question asking where they lived).

Illness prevented the coordinators of the Hadrian Support Group, which operates within Tyne and Wear, from giving the same degree of support, but we were nevertheless able to benefit from their assistance. We recruited at least 11 participants via this group and/or Dr John Mansfield, Consultant Gastroenterologist at the Royal Victoria Infirmary, who passed on our questionnaire to patients at some of his clinics.

In all, we received information from 27 people. Full profiles for the participant group are included at Appendix 1.

2.2.2 Focus group

Seven patients took part in the focus group, of the 10 who initially agreed to participate. Six of the attendees were female. Five were colitis patients and two had Crohn's. All seven were recruited with the help of the Durham and Wearside Crohn's and Colitis Support Group.

2.2.3 Telephone interviews

Three people were interviewed by telephone. Two of these were male. All three were Crohn's patients. All three had expressed interest in taking part in the focus group, but in practice the routines imposed by their conditions did not fit into the time slot that best suited most other participants.

2.2.4 Questionnaires

Of the 17 people who completed questionnaires, 12 were female and five were male. Nine people had Colitis, seven had Crohn's Disease and one had Collagenous Colitis.

2.3 Focus group format

We developed a set of questions to cover the following areas:

- Diagnosis, treatment and levels of information and advice received
- Experiences of care received and suggestions for improvements
- Experiences of medication and suggestions for improvements

- Impact of IBD on daily lives and on long term life and career choices

We also gave respondents the opportunity to identify and discuss any other issues they regarded as relevant to Inflammatory Bowel Disease.

2.4 Questionnaire format

We developed the questionnaire to address exactly the same issues as the focus group, using a combination of multiple choice boxes and free comment sections.

The questionnaire is included in this report as Appendix 2.

Questionnaire responses are set out in Appendix 3.

Section 3 - Findings

3.0 Findings

This section provides a summary of the findings of the patient involvement undertaken for the project.

Where participants mention UC and CD, they are referring to Ulcerative Colitis and Crohn's Disease.

3.1 Experiences of diagnosis

3.1.1 Onset of symptoms

We began by asking how old our participants were when they first noticed their symptoms. Ages varied from 9 to 62, with the majority clustered in the mid twenties. However, some participants felt with hindsight that they may have been manifesting symptoms before they really took note:

"I was diagnosed when I was 40, but looking back I think I had an inclination when I was only in my early twenties."

"Looking back over my life I remember having an accident when I was in the junior school, when I was in my teens, in my twenties. But I was never going to the doctor's for this."

3.1.2 Delay between symptoms and going to a GP

Patients varied significantly in the time it took them to consult their GP after noticing symptoms: most saw a doctor within one month, although a significant minority experienced symptoms for a year before consulting their GP. Everyone who delayed for a year did so because they were initially "too embarrassed" to see a doctor. Others who delayed for less than a year often said that at first they thought it was "just a bug or virus", or "something I'd eaten".

3.1.3 Diagnosis times

Diagnosis times also varied, from less than a month to nine years. One patient had been admitted to hospital almost immediately and diagnosed in less than a week. Everyone who was diagnosed within three months expressed satisfaction at the time taken, while those whose diagnoses took longer invariably regarded the process as "too long".

Some people talked about long delays characterised by distressing experiences:

"I went back to the doctor's and they kept saying to me 'No, you're fine. You're fine. You're fine.' But I knew I wasn't, and for six weeks I rang the doctor's on a weekly basis to say 'I've still got diarrhoea I can't sleep with it.' [. . .] It wasn't until I was

prescribed anti-diarrhoea tablets that nearly made me burst, that they realised that I had Colitis.”

“By the time I got diagnosed I was so critically ill I was down to five and a half stone.”

Other participants’ conditions went undiagnosed when their symptoms did not match up with ‘normal’ patterns of IBD:

“My mum thought I might have Crohn’s, but the GP insisted it couldn’t be that because I was too young. She prescribed medication that my consultant has now told me was the worst possible stuff for Crohn’s.”

One patient’s Crohn’s disease went undiagnosed for many years because his blood tests repeatedly returned a negative result:

“No blood test I have ever had has shown positive for Crohn’s”

3.1.4 Changes in diagnosis times

Some older participants, who had had IBD for many years, suggested that perhaps their experience of delayed diagnosis would have become less common as medical knowledge and understanding have developed:

“This was a long time ago. I think things would be dealt with faster now.”

However, this was not borne out by our research – the most recently diagnosed participant had been presenting with symptoms for nine years before her diagnosis.

3.1.5 GP responses

While a significant number of patients had to cope with continual misdiagnoses of ‘yuppie flu’, anorexia and ‘nervous stomach’ others were full of praise for GPs who acted swiftly and took their symptoms seriously from the start:

“My GP diagnosed me at the first appointment, phoned the hospital, gave me steroids, then I had a colonoscopy. This all happened during Christmas and New Year, so very speedy.

“GP was wonderful - kept phoning hospital to chase them.”

3.2 Information, advice and support

3.2.1 Developments over the years

Overall, the majority of patients felt they had received very little information or advice about their condition once they were diagnosed. There appeared to be no significant divergence in this respect between people who were recently diagnosed and those who had had the condition for some time:

“At the time of being diagnosed, apart from a diagram of the intestines, I was given no information about Crohn’s and what to expect. This was pre-internet and so it was not so easy to get information. My mum had a medical book that she referred to.”

One of the more recently diagnosed respondents said she had received “no information whatsoever.”

One patient, however, who was diagnosed nine years ago at the age of 10, said:

“The staff at the RVI [Royal Victoria Infirmary, Newcastle] have always been really good at explaining everything.”

3.2.2 Non-medical sources of information and support

Opinions about the level and quality of information and support available varied considerably.

The internet has proved to be a useful source of information, leading many people to the support offered by organisations like Crohn’s and Colitis UK (also known as NACC) through searching :

“I went onto internet and found NACC. Rang the info line which was very helpful.”

“When I was first diagnosed I was clueless, had no information. I found NACC online, became a member and now I know everything I need to. The support in the early days was fantastic. I am still a member and fundraiser, I could not have coped without the group.”

3.2.3 GPs and consultants

GPs in general appear to offer very little information, and the information consultants give clearly varies in terms of accessibility and quality:

“Doctors need to be much more knowledgeable about UC and CD - in my view they do not take it seriously enough.”

“I asked the consultant in hospital a couple of times to try and talk me through it and I couldn’t understand it because he talked in very consultancy terms.”

“My consultant, and the whole team at the RVI, have always been very good and explained everything to me so I understood.”

Some patients spoke of receiving initial support from their GPs, which tailed off:

“She [GP] was brilliant in the beginning and then [. . .] she said to me ‘look you’ve got UC, you’re always going to have UC’, which I hadn’t twigged up until that point, ‘get over it, get on with it’.”

“I’ve just had a medical review with the GP and it’s sort of like ‘off you go, just get on with it’.”

“I have no confidence at all in my GP dealing with or recognising the symptoms of UC or CD. Only training, I guess, can improve that.”

Another focus group participant changed GPs after ‘continual misdiagnosis’ and is now very satisfied with the care she receives:

“I have to say since I’ve changed GPs back to one that I can trust, he’s fantastic and he’s very thoughtful because obviously it impacts, because of the medication that I now take, it impacts on a lot of other things and he’s very mindful of that when I go about any condition.”

3.2.4 The impact of strong support

Some people mentioned being given ‘a couple of leaflets’, but by far the most widely praised source of support for focus group participants was a specialist IBD nurse in County Durham who was variously described as ‘fantastic’, ‘amazing’ and ‘brilliant’:

“I have to say she’s been fantastic, she gave me a pack with loads of information in, she talked through the condition with me and since then I’ve rung her on a couple of occasions about a few queries that I’ve had around my medication and some of the lifestyle things and she’s been fantastic.”

3.3 Experiences of hospital treatment

We asked participants about their outpatient and inpatient experience of hospital, and also canvassed opinion on receiving some treatment at home from a nurse.

3.3.1 Outpatient experience: getting to hospital

Most people were broadly satisfied with their regular outpatient experience.

Travel arrangements featured in a significant number of responses to this question – participants spoke about the anxiety created by traffic delays or parking problems, and their inevitable impact on symptoms. Most, however, had devised strategies or enlisted help to minimise potential problems.

The majority attended hospitals close to home, and many appreciated being able to attend local clinics or community hospitals for some outpatient appointments.

However, one long-term patient spoke in a telephone interview about his frustration at being ‘moved’ from one consultant – and hospital – to another, which will involve much more complicated travel arrangements. He plans to ask whether tests ordered by his new consultant in Newcastle can be carried out in Durham, to avoid frequent longer journeys.

Another patient, who attends outpatient appointments every two to three weeks at the RVI, mentioned the difficulty of finding parking space in the hospital's multi-storey car park:

"I have to go make sure I'm parked by 9am regardless of when my appointment is – otherwise I can't be sure I'll get a space."

3.3.2 Outpatient experience: appointments

Most participants who had regular outpatient appointments expressed satisfaction at their overall experience. The times taken varied from 30 minutes (for regular treatments) to up to half a day for consultant appointments; but most people were understanding about long waiting times:

"The appointment can be anything from a few minutes to 20-30 minutes if there has been a change in my condition. I sometimes have to wait a long time after my appointment time before I am seen, but I have no complaints about this as it is because the consultant gives each patient the time they need and I benefit when I need a longer appointment."

Many patients also said their consultant was easy to contact if they needed to speak between appointments. A few, however, expressed frustration that their only access to the consultant was via their GP.

3.3.3 Inpatient experience

Most respondents had had some experience of overnight stays in hospital. Of these, all had had at least one emergency admission and about half had also been admitted for planned surgery.

Experiences varied – some participants reported general satisfaction, but most had encountered problems, usually caused by lack of specialist knowledge by staff; inadequate or unhygienic toilet facilities; or location in inappropriate wards.

Satisfaction with the RVI in Newcastle was generally higher than with other hospitals in the region:

"Very good. Both the ward staff and my consultant's team are very sympathetic and understanding of my condition."

"You can tell the staff on the ward are clued up and specialise in this kind of condition. And they usually put me in a cubicle on my own. I don't have to ask them to – they just do it."

"I was always well looked after."

Even here, however, a patient who found herself in non-specialist ward at the RVI reported:

“Some staff on older people’s ward did not understand the condition and were intolerant of its effects.”

This lack of understanding by non-specialist staff emerged as a common theme across all hospitals in the region:

“Need more IBD aware staff. I have always found that staff don’t know anything about Crohn’s.”

Several people commented that they would have preferred more age-appropriate or condition-appropriate wards. One participant who had stayed in two different hospitals reported:

“My experience of all the wards I have stayed on has been awful. There are usually several elderly patients, some of which are dying and one that shouts all night. [. . .] I was even on an adult ward when I had my operation at 16. I was there for six weeks and it was really scary. An age-appropriate ward would have been much better.”

Toilet facilities also created significant problems, and several respondents identified a need for better facilities for IBD sufferers:

“There are never enough toilets and the level of cleanliness is poor as they are used by old people with incontinence. On a gastro ward in particular, it would be nice if the toilet facilities gave you more privacy. I got moved to a private room once with en-suite bathroom – it was bliss.”

“I was in a large bay with a toilet down the corridor used by lots of patients.”

- 3.3.4 There was a mixed reaction to suggestions that home visits for some treatments might be helpful. Many were neutral and some said they preferred going to clinics or hospitals; but others welcomed the idea, especially if they had regular appointments for injections or other treatments:

“I attend Sunderland Royal Hospital for six-weekly intravenous infusion. These appointments take about 3.5 to 4 hours out of my day, including the two hours it takes to administer the treatment. It would be really useful if the intravenous infusion could be given to me at home by a nurse.”

“That’s quite a good idea as it would save the worry of having to get to hospital.”

3.4 Experiences of medication

3.4.1 Range of medication

Participants listed a wide range of medication between them, but many were common to most people and included steroids, anti-diarrhoea medication, painkillers, vitamin and other supplements, anti-nausea treatments and anaemia medication. These addressed the specific symptoms of IBD and, in many cases, the joint pain that often accompanies the conditions.

Some participants also took nutrition internally overnight via a 'peg'.

3.4.2 Experience of taking medication:

Overall, most participants had adapted to their medication regimes and took a pragmatic approach. Most took their medication exactly as directed by their consultant:

"I take exactly what I have been prescribed as directed – because that is what has been recommended and I know it is the best treatment available."

Some have made minor adjustments over time, and several reported adverse side effects from taking iron tablets:

"I was prescribed iron tablets but they made me feel ill in the morning so I stopped taking them. I have not told my consultant."

Others talked about the confusion and doubt created by having to take large quantities of different types of medication:

"I swallow them all down at the same time in the morning. I'm not sure if this is strictly correct, but the directions I have been given are no clearer than, for example, 'to be taken three times a day'. I have just developed a system over time that suits me."

One focus group participant had taken the decision to stop all her medication and control the condition entirely through diet. She had become convinced that the medication was actually making her worse:

"Well there was one particular weekend when I thought I'd be better off if I was dead quite honestly, it was that bad the pain and I just couldn't take it anymore [. . .] I thought, if anything bad happens it can't be any worse than this and within two or three days I started feeling 100% better."

Some participants mentioned the practical difficulties of taking rectal suppositories as opposed to tablets, and one also said:

"I had some difficulty a short while ago injecting the Humira, but I resolved that problem."

3.4.3 Meeting the cost of medication

Some people in the focus group mentioned the expense of taking large quantities of different medication.

In most cases, GPs had alerted patients to the advantages of prescription pre-payment certificates which were unanimously agreed to pay for themselves almost immediately.

Others, however, talked of 'stumbling upon' that information after a period of spending up to £50 per month on prescription charges.

Some people expressed irritation that they were not entitled to free prescriptions:

“Everybody else with diabetes, epilepsy, asthma, they get free prescriptions but if you have UC or Crohn’s you can’t get free prescriptions. But it is for life, it’s not something that’s going to disappear.”

3.5 Managing IBD symptoms

Participants’ views on how best to manage symptoms – and their experience of what exacerbated or alleviated them – varied a great deal, highlighting the variations in experience of IBD and the difficulty of identifying universally effective treatments or lifestyle changes.

3.5.1 Medication

Different participants had very different views on what improved their symptoms. Some people saw medication as the only really effective solution:

“My symptoms are now fairly stable but I know that if I stopped taking the medication the pain etc would return. I feel in control but my condition is heavily managed by the medication I take, they are my first line of defence.”

3.5.2 Diet

Other participants were more concerned about the impact of lifestyle and diet. Food featured prominently in many people’s management strategies, but the foods that triggered flare-ups varied significantly from patient to patient:

“Anything greasy or fatty makes me worse, and I know now that I can’t have anything like Coke or Lucozade – they have an instant effect!”

Some people identified certain vegetables (cabbage and broccoli were notable culprits), dairy foods and bread, while others felt that times of eating were more significant than the actual foods eaten:

“I’ve stopped eating first thing in a morning now, I don’t tend to eat very early at all, towards dinnertime before I start having something to eat because if I do I know I’m going to go a couple of times.”

“I find eating on a night as well – you know, having a late meal – didn’t work for me either, about 5 o’clock is my knock off point. I would like my meal about 5 o’clock on a day and that’s the best time of day because then it had time to digest itself and get itself sorted out and then I might, luckily, hopefully, not have to get up that night, you know to go to the toilet.”

Alcohol seemed to affect different people in different ways. Most people had experienced problems with alcohol and now avoided it altogether or drank very rarely, but others found that small quantities had no effect or even helped to alleviate symptoms:

“If I drink wine early on the night, a couple of glasses of wine I’m fine, I don’t need the toilet. Whether it’s a type of a anti diarrhoea drink I don’t know.”

3.5.3 Stress

Stress featured prominently in almost every participant’s experience of IBD.

“Stress of any kind makes my condition worse.”

One participant felt that he coped well with work-related stress, but was badly affected by more apparently trivial stress triggers:

“I cope with a reasonably stressful job, but the stress of my car being off the road and having to get a taxi, for example, will have a big effect on me.”

Some people had taken positive steps to manage their stress:

“I try to take time out to de-stress and I use meditation tapes.”

“I did some stress management counselling and that was fantastic. They gave you specific tools and techniques to use to manage how you felt about your illness that day or how your symptoms were and it had a positive effect.”

Some participants had been advised by their consultant to take specific stress-control measures, but one participant’s employer had encouraged, and paid for, her to attend stress management courses run by MIND.

3.5.4 Lifestyle changes

Almost everyone who participated had had to make some changes to their lifestyle to accommodate their condition and manage their symptoms. Exercise was frequently identified as a major factor in managing both the physical and emotional impact of IBD:

“I’ve found walking really helps me, it helps me with the pains and it helps lift my mood a little bit as well. If I’m really struggling, I just try and get myself out for a walk.”

“It helps if I take plenty of exercise - football, running, cycling etc.”

“I’m a keen cricketer. I enjoy it and I train hard, although sometimes my Crohn’s makes me too knackered for it.”

“I try to exercise when I am well enough and I am also going to start reflexology.”

For some participants, however, IBD has forced them to give up physical activities they used to enjoy:

“In flare-up times I can’t be far from toilets – so hill-walking has had to stop.”

Overall, while some participants talked about ‘falling off the wagon’ from time to time, everyone had accepted the importance of managing their symptoms and making the necessary adjustments:

“I just make changes to my life as and when necessary. I don’t really think about it, you just do what you need to do to keep well. I behave sensibly as it makes it worse to do something silly like drink alcohol. When you feel ill a lot of the time it isn’t worth doing things that you know are guaranteed to make you worse.”

“Some days I decide to just do whatever it is I want to do, and usually I regret it.”

3.6 Living with IBD

We asked participants to tell us about their experience of living with IBD, from daily routines to major lifestyle decisions. It was clear that everyone had made significant adjustments to cope with their particular condition.

3.6.1 Daily routines

While some participants felt that their IBD had receded to a level that did not currently affect their daily routines, most experienced at the very least ‘good days and bad days’ and the impact for a number of people was dramatic:

“My condition is always on my mind. It takes up a lot of brain power. I have to consider: what will happen if I’m ill while I am out of my home, what I’m going to eat. If I’m not well when I go to work I am thinking about how long it will be before I can get home again. It is always at the front of my mind and the medication I take is a daily reminder.”

“Since the surgery I usually have an upset stomach in the morning when I get up and later after I have got to work and again later in the afternoon. However despite keeping a routine and planning my day the IBD can occasionally throw a left fielder and I can suffer flare-ups.”

“I spend a couple of hours in the morning and the same at night to sort out my bowel habits/problems.”

The unpredictability of IBD also featured in participants’ response to their condition:

“I can be really well and then my condition will flare up so quickly and badly that I will be admitted to hospital.”

A number of participants also mentioned the ‘Can’t Wait’ card, which states that the card holder has a medical condition causing urgent need for a lavatory. Most people found the card useful although some were embarrassed to use it. One participant recalled an occasion when hospital staff refused her permission to use a ward lavatory as she passed through on her way to a NACC meeting.

3.6.2 Personal lives and relationships

A number of respondents spoke about the impact of their condition on their personal lives:

“I think it has affected my relationships, that had it not been for Crohn’s I may have now been married with children. But it is hard to meet a man and to then explain this side of my life to him.”

“I am a widow and feel having IBD stops me entering into another serious relationship - the intimate side really worries me. What if I'm at his house and need the toilet in a hurry? The smells, the noise. My late husband was used to it but I developed Colitis during our marriage and didn't need to bring up the subject.”

Participants who were diagnosed while very young were also sharply conscious of not being able to take part in the usual rituals of growing up:

“When I was a teenager Crohn’s stopped me from going to parties and experiencing the same social pursuits as other teenagers as I was ill a lot of the time.”

3.6.3 Work

Two people mentioned the impact of IBD on their careers:

“I have turned down two offers of employment on this account. Self employment is the solution.”

“My career has probably been affected by my condition. I had to stop travelling about five years back. I used to travel internationally for my work, but had to stop because of the symptoms.”

Employers seemed to vary in their willingness or ability to accommodate the impact of IBD. Positive support included paying for a stress management course and allowing one employee to change his working hours in order to be at work during the least volatile part of his day.

A few people had been given reserved car parking spaces, which reduced the stress involved in not being able to park close to the office. A significant number spoke about the anxiety and embarrassment of having to leave meetings frequently and without warning, and also about the lack of adequate facilities at work:

“We have five staff and one toilet, but workmates are really good and now understand fully – but it is embarrassing for me!”

However, respondents who were in work were generally determined not to let their condition affect their working lives:

“There was a point where I thought that I wasn’t going to be able to work because of the lethargy and the pain and stuff and the side effects of my medication. I thought ‘I can’t do this’ but I do, I work full time but Sunday is the day when I don’t really get out

of my pyjamas. If I do get out of my pyjamas then I get washed and I just go for a little walk locally because I am exhausted – but I love my job so that’s one of my balances.”

3.6.4 Tiredness

Asked which symptoms were most limiting in terms of carrying out daily activities, a significant proportion of respondents identified tiredness. This may be the effect of living with a long term debilitating condition, as well as a side effect of particular medication, for example methotrexate. Some described the feeling as ‘more than tired’ and talked about being unable to do anything when it overtook them:

“Tiredness also is a huge factor, some days it’s like running into a brick wall and I don’t feel people understand, they just seem to think you need an early night. Some nights I finish work, have an hour’s sleep on the sofa, have dinner then go to bed for eight or nine hours and don’t feel any better for it.”

“Tiredness and pain are some of the worst things – sometimes you can’t do anything.”

3.6.5 Living a ‘normal’ life

Asked to what extent their IBD prevented them from having a ‘normal’ life, most participants acknowledged the restrictions imposed by their condition but many were determined not to let it spoil their lives:

“I like to think it won’t stop me doing things. I am adamant that it won’t change my life.”

“It’s important to keep a positive outlook on life. Although I can no longer walk as far as I used to - I can still walk!! My appetite is not as good as it used to be but I still like to go out for a meal with my family. We still go dancing 2-3 times a week. If your friends and family know about how IBD affects your life they can be very supportive and encouraging. Having a good consultant also makes a difference.”

“You cannot just say ‘oh I can’t do that’, you just work it out, chip at it every day.”

The importance of good advice and support emerged again here as an influential factor. The specialist IBD nurse mentioned elsewhere in this report received unstinting praise for her work in encouraging patients to live their lives to the full:

“The very first time I met her she said ‘you know you have a life first, that’s the most important thing’.”

“She very much encourages you to do what you would want to do, be mindful of it but just continue on.”

3.7 Additional comments

3.7.1 Partners and carers

Our research did not include questions about partners or carers; but it very soon became clear that their role and contribution were crucial.

There was general agreement when one focus group member said she felt families needed 'a medal the size of a frying pan' for all their help in living with IBD.

One participant talked about the 'brilliant' support she received from her husband:

"My husband, when he got a sat nav he had every toilet marked up on the sat nav and he used to take it walking so even if we were in the street doing the shopping, he knew exactly, if I said I want to go to the toilet, he knew where the nearest toilet was."

However, a number of respondents were acutely conscious of the demands and limitations their condition places on family members:

"I feel guilty as my husband is still very fit and loves walking, cycling and climbing."

One respondent talked about realising how distressing her condition can be for her partner:

"My husband is the most fantastic supportive man in the world, he's brilliant and he's held my hand all the way through it, but I'm doing a talk at the next NACC meeting and I said 'are you going to come?' and he said 'no, because I can't re-live that again' – because of how poorly I was. He said 'I can't do that again, I can't talk about that again, I can't go there'."

3.8 Summary

It is clear from this research that IBD creates a wide range of debilitating and limiting challenges for patients, and that both Crohn's Disease and Colitis carry with them a complex set of symptoms. The nature and severity of those symptoms, and their impact on people's lives, vary from patient to patient but are almost always difficult to accommodate and overcome.

The next section of this report contains some recommendations that could lead to better experiences for patients and carers.

Section 4: Recommendations

4.0 Recommendations

This section contains recommendations for possible changes of approach or emphasis in the treatment of IBD, based on the experiences of the patients we consulted for this research.

Many of the measures listed below are already in place and employed by some GPs, consultants, nurses and hospitals in the region. We have included them because they were specifically identified as examples of good practice by our participants.

4.1 Diagnosis

Patients who commented on their experience of diagnosis made the following recommendation:

- Symptoms of IBD are so diverse in type and severity that it should be recognised as a possibility and thoroughly investigated wherever abdominal pain or diarrhoea are present

4.2 Information, advice and support

- Provide more comprehensive information (leaflets, NACC contact details) etc in GP surgeries
- Consider GP surgery/consortium education sessions for IBD patients to share information and advice about living with and managing their condition
- The pack provided by the IBD specialist nurse in Durham could provide a model for other areas to adopt
- Some respondents who did not live in Durham said they would like to be referred to a specialist Health Support Worker
- Carers need support too – an information pack for carers would be well received
- Ensure patients know about, and can access, a 'Can't Wait' card
- Increase awareness of the 'Can't Wait' card among health professionals and the wider population

4.3 Experience of hospitals

4.3.1 Outpatient experience

- Consider allowing patients who have to travel for outpatient appointments to have their tests administered in hospitals or clinics closer to home
- Consider the practicalities of delivering some outpatient treatments (e.g. infusions) in patients' homes
- Consider providing dedicated parking space for IBD patients – the anxiety involved in trying to park for hospital appointments (especially at the RVI Newcastle) can exacerbate symptoms

4.3.2 Inpatient experience

- Where possible, place patients in specialist Gastro wards (ensuring that staff in those wards are aware of the specific implications of IBD)

- Ensure staff in non-specialist wards are aware of IBD symptoms and prepared to make arrangements to accommodate their toilet needs
- IBD patients need access to clean and adequate lavatories

4.4 Medication

- Provide information about prescription pre-payment certificates at the point of diagnosis
- Ensure patients understand which medicines can be taken together, and the potential side effects of each

4.5 Managing symptoms and Living with IBD

- Consider whether patients with acute urgency could be eligible for a 'blue badge' to facilitate parking near the necessary facilities
- Encourage patients to exercise and try to live 'normal' lives, without appearing to dismiss their problems
- Encourage, and where possible facilitate, mutual support between patients
- Consider the impact of IBD on carers and other family members as well as on the patients themselves, and the extent to which that impact may affect their health and wellbeing

Appendices

Appendix 1

Participant profile: Focus Group and Telephone Interviews

Gender	Frequency	%
Male	3	30
Female	7	70
No response	0	0
Total	10	100.0

Age	Frequency	%
16 – 30	2	20
31 – 59	4	40
60+	4	40
No response	0	0
Total	10	100.0

Where do you live?	Frequency	%
Peterlee	2	20
Birtley	1	10
Durham	2	20
Haswell, County Durham	1	10
Consett	1	10
Chester le Street	1	10
Jarrow	1	10
Corbridge, Northumberland	1	10
No response	0	0
Total	10	100.0

Ethnicity	Frequency	%
White British	10	100
No response	0	0
Total	10	100.0

Condition	Frequency	%
Crohn's Disease	5	50
Ulcerative Colitis	5	50
No response	0	0
Total	10	100.0

Participant profile: Questionnaires

Gender	Frequency	%
Male	5	29.4
Female	12	70.6
No response	0	0
Total	17	100.0

Age	Frequency	%
16 – 30	0	0
31 – 59	6	35.3
60+	9	52.9
No response	2	11.7
Total	17	100.0

Where do you live?	Frequency	%
Newcastle upon Tyne	3	17.6
Northumberland	1	5.9
Morpeth	1	5.9
Ashington	1	5.9
Haltwhistle	1	5.9
North Shields	1	5.9
Gateshead	1	5.9
Whickham	1	5.9
Peterlee	1	5.9
Chester le Street	1	5.9
Durham	1	5.9
Consett	1	5.9
No response	3	17.6
Total	17	100.0

Ethnicity	Frequency	%
White British	17	100
No response	0	0
Total	17	100.0

Condition	Frequency	%
Crohn's Disease	7	41.1
Ulcerative Colitis	9	52.9
Collagenous Colitis	1	5.8
No response	0	0
Total	17	100.0

Inflammatory Bowel Disease (IBD) Questionnaire

Community Action on Health (CAOH) is collecting information about the care and treatment experiences of people with IBD. The information we gather will be fed back and used to improve the treatment and care available for patients.

We would really appreciate it if you could take some time to complete this questionnaire.

ABOUT YOU

Gender

Female Male

Transgender

Age

16 – 30

31 – 59

60+

Where do you live? E.g. Newcastle, Sunderland, Durham

.....

Please indicate your ethnic background

White	<input checked="" type="checkbox"/>	Asian or Asian British	<input checked="" type="checkbox"/>
British		Indian	
Irish		Pakistani	
Any other White background		Bangladeshi	
Mixed		Any other Asian background	
White and Black Caribbean		Black or Black British	
White and Black African		Caribbean	
White and Asian		African	
Any other mixed background		Any other Black background	
Other ethnic groups			
Chinese			
Any other ethnic group (<i>write in</i>)			
.....			

Experiences of diagnosis

What type of Inflammatory Bowel Disease have you been diagnosed with?

Ulcerative Colitis Crohn's Disease

How old were you when you first noticed your symptoms?

.....

How long did it take you to consult a GP after noticing the symptoms?

.....

If you didn't go to your GP straight away, why was this?

.....

From first visiting your GP, how long did it take for you to be given a diagnosis of IBD?

Less than 1 month 1-3 months

4-6 months 7 months-1 year

More than a year

Did you feel this timescale was:

About right Too long

Do you have any comments about this?

.....

.....

After diagnosis, what information were you given to help you understand the condition? (you can tick✓ more than one box)

I can't remember if I was given any information

No, I wasn't given any information or advice

Yes, my GP/consultant gave me some leaflets

Yes, my GP/consultant put me in touch with Crohn's and Colitis UK (NACC)

Yes, my GP/consultant gave me other information (please specify)

Other (please state)

Were you given the opportunity to discuss your treatment options? Yes No

Thinking about the support you receive from your GP / consultant. Do you feel that it meets your needs? Yes No

If no, what extra support would you like to see provided?

More support from my GP Help with taking medication

More support from my consultant Additional information / education

Regular progress reports Other (please state)

What kinds of non medical / informal support do you receive for your IBD?

Patient support groups Support from employer

IBD Helpline Other (please state)

Support from family and friends

Is there any other non medical / informal support that would be helpful to you?

.....

.....

Experiences of hospital treatment

Thinking about outpatient visits to hospital for your IBD

How do you get to your hospital appointment and how easy is this?

Is your appointment usually on time? Yes No

How much of your day does your appointment normally take?

How would you feel about receiving your hospital treatment at home from a nurse?

Have you ever had to stay overnight in hospital as a result of your IBD?

Yes No

Was this an emergency or planned admission? Emergency Planned

Which hospital were you treated at?.....

What kind of ward were you on?

General Medical ward Surgical ward

Older peoples ward Specialist ward

Other (please state)

What was your experience of being an inpatient with IBD?

.....
.....
.....
.....

Could anything have been improved about your stay? (Please tick all that apply)

No Yes, more privacy

Yes, a more condition appropriate ward Yes, more adequate toilet facilities

Yes, a more age appropriate ward Yes, more IBD aware staff

Other (please state)

.....
.....
.....

Experiences of medication / treatment

What type of medication do you take?

- | | | | | | |
|------------------|--------------------------|--------------------|--------------------------|---------------------|--------------------------|
| Aminosalicylates | <input type="checkbox"/> | Anti diarrhoeal | <input type="checkbox"/> | Vitamin Supplements | <input type="checkbox"/> |
| Steroids | <input type="checkbox"/> | Bulking Agents | <input type="checkbox"/> | | |
| Painkillers | <input type="checkbox"/> | Anaemia treatments | <input type="checkbox"/> | | |
- Other (please state)

Do you have any problems taking your medication?

- | | | | |
|----------------------------|--------------------------|-----------------------------|--------------------------|
| No | <input type="checkbox"/> | Yes - side effects | <input type="checkbox"/> |
| Yes – timing of medication | <input type="checkbox"/> | Yes – how I have to take it | <input type="checkbox"/> |
- Other (please state)

Do you take your medication as directed by your GP / consultant?

- | | | | | | |
|-----|--------------------------|----|--------------------------|------------------|--------------------------|
| Yes | <input type="checkbox"/> | No | <input type="checkbox"/> | Most of the time | <input type="checkbox"/> |
|-----|--------------------------|----|--------------------------|------------------|--------------------------|

If you do take your medication as directed, what are your reasons for this?

- | | |
|---|--------------------------|
| I have been told to take them | <input type="checkbox"/> |
| My medication keeps me well / makes me feel better | <input type="checkbox"/> |
| I know I will feel worse if I don't take it as directed | <input type="checkbox"/> |
- Other (please state)

If you don't take your medication as directed, what are your reasons for this?

- | | | | |
|--------------------------------|--------------------------|--|--------------------------|
| Side effects | <input type="checkbox"/> | I forget | <input type="checkbox"/> |
| Inconvenient / complicated | <input type="checkbox"/> | I don't think its making any difference | <input type="checkbox"/> |
| Lack of necessary privacy | <input type="checkbox"/> | Reacts badly with other things | <input type="checkbox"/> |
| I don't like taking medication | <input type="checkbox"/> | I prefer to manage my symptoms in other ways | <input type="checkbox"/> |
- Other (please state)

Have you ever spoken to your GP / consultant about any concerns you have about your medication? If so, what happened?

.....

.....

.....

Is there anything that would make it easier for you to take your medication?

.....

.....

.....

Do you have any other comments about the care you receive for your IBD and your medication?

.....

.....

.....

Experiences of managing your IBD symptoms

Is there anything that makes your symptoms worse?

.....

.....

How do you manage this?

Avoid things that make me worse Take medication to prevent symptoms
Change routine to accommodate symptoms I just deal with it
Other (please state)

Apart from your medication, is there anything that makes your symptoms better?

.....

.....

How did you find out about the things that make your symptoms better?

By accident / trial and error Support group / other people with IBD
GP / Consultant Leaflets / Internet
Other (please state)

How easy do you find it to make changes to your lifestyle in order to manage your symptoms?

There isn't anything I can change
Easy because it keeps me well
Easy most of the time but sometimes I 'fall off the wagon'!
Difficult, but I do it anyway
There are things I should avoid but I enjoy them
I take medication to manage any problems
GP / Consultant
Other.....

How far would you agree that your GP or consultant treats the symptoms that are important to you?

Strongly agree Agree
Disagree Strongly disagree

If you disagree with the above questions, can you give an example of how this hasn't happened?

.....

.....

.....

How could this be improved for you?

.....

.....

.....

If you are a member of a support group or organisation for IBD, has this been any help to you?

.....

.....

.....

Experiences of living with IBD

How does IBD affect your daily routine?

Is this different during periods of flare up and remission?

What symptoms do you find most limiting in terms of carrying out daily activities?

Are there any activities that you no longer do or are unable to do as a result of having IBD?

How does this make you feel?

Please use the space below to tell us anything else you would like to share regarding living with IBD

.....

Thank you for taking the time to complete this questionnaire

Please return it, in the envelope provided to:

**FREEPOST
Community Action on Health**

Appendix 3

Questionnaire responses

Experiences of diagnosis

How old were you when you first noticed your symptoms?

- 19 x2
- 26 x2
- 27
- 29
- 31
- 34
- 38
- 42
- 55
- 58
- 61
- 62
- 65
- 67

How long did it take you to consult a GP after noticing the symptoms?

- Immediately
- 1 week x2
- 3 weeks
- 1 month x3
- 2 months x2
- About 6 weeks
- 1 year x4
- I didn't consult a GP
- It was not until I was admitted to hospital as an emergency that it was diagnosed
- I was diagnosed in hospital

If you didn't go to your GP straight away, why was this?

- I thought it was just a bug or virus x2
- I thought it was something I'd eaten
- I was embarrassed x3
- My symptoms came and went; when they returned I went
- It was only happening from time to time
- I thought things would improve naturally
- I hoped it would go away
- I underwent emergency surgery in 1978 and was told then that in was Crohn's
- I did go to my GP but he was of no help at all
- Not answered x5

From first visiting your GP, how long did it take for you to be given a diagnosis of IBD?

	Frequency	%
Less than 1 month	3	17.6
1-3 months	5	29.4
4-6 months	3	17.6
7 months-1 year	2	11.8
More than a year	2	11.8
No response	2	11.8
Total	17	100.0

Did you feel this timescale was:

	Frequency	% of responses
About Right	8	47.1
Too Long	7	41.2
No response	2	11.7
Total	17	100.0

Do you have any comments about this?

- 50 years ago there was not as much was known about Crohn's. It became frightening as time went by because of the weight loss and pain and being in and out of hospital
- I lost 4 1/2 stone in approximately 6 weeks. I felt this was enough to speed up the process. My GP was wonderful. He kept phoning the hospital to chase them up
- It was in 1977 when I became ill and very nearly died. At that time I was going to my GP but he did not recognise what was wrong
- My GP diagnosed me at the first appointment, phoned the hospital and gave me steroids. I then I had a colonoscopy. This all happened during Christmas and New Year, so it was very speedy
- Long time ago. I was a student nurse when I was diagnosed and had the best treatment that was available at the time
- It was quick from GP to consultant referral
- I was admitted to hospital almost immediately and diagnosed in less than a week
- It was my surgeon who diagnosed Crohn's disease and as the damaged tissue had been removed, I did not see the need to then go to my GP
- My GP acted immediately. The gastroscopy and colonoscopy didn't show it. She queried collagenous colitis and organised a sigmoidoscopy for the following day. I had to wait 3 weeks for the result which showed collagenous colitis
- It was made clear to me that Crohn's existed within a broader spectrum of IBD
- This was a long time ago. I think things would be dealt with faster now
- Not answered x6

After diagnosis, what information were you given to help you understand the condition? (you can tick✓ more than one box)

	Frequency	% of responses
I can't remember if I was given any information	2	8.3
No, I wasn't given any information or advice	5	20.8
Yes, my GP/consultant gave me some leaflets	7	29.2
Yes, my GP/consultant put me in touch with Crohn's and Colitis UK (NACC)	7	29.2
Yes, my GP/consultant gave me other information (please specify)	0	0.0
Other (please state) <ul style="list-style-type: none"> • Verbal information • Each stage of diagnosis explained • Very basic information 	3	12.5
No response	0	0.0
Total	24	100.0

Were you given the opportunity to discuss your treatment options?

	Frequency	% of responses
Yes	7	41.2
No	10	58.8
No response	0	0.0
Total	17	100.0

Thinking about the support you receive from your GP / consultant. Do you feel that it meets your needs?

	Frequency	% of responses
Yes	11	64.7
No	6	35.3
No response	0	0.0
Total	17	100.0

If no, what extra help would you like to see provided? (you can tick✓ more than one box)

	Frequency	% of responses
Not answered	9	39.1
More support from my GP	5	21.7
More support from my consultant	2	8.7
Regular progress reports	2	8.7
Help with taking medication	0	0.0
Additional information / education	3	13.0
Other (please state)	2	8.7
<ul style="list-style-type: none"> • Diet and blue badge would be useful • Referral to a Health Support Worker 		
No response	0	0.0
Total	23	100.0

What kinds of non medical / informal support do you receive for your IBD? (you can tick✓ more than one box)

	Frequency	% of responses
Patient support groups	8	29.6
IBD Helpline	2	7.4
Support from family and friends	12	44.4
Support from employer	3	11.1
Other (please state)	2	7.4
<ul style="list-style-type: none"> • None. I feel isolated • Recently the Colitis and Crohn's Group on Wearside contacted me. Hopefully some good will come of it. 		
No response	0	0.0
Total	27	100.0

Is there any other non medical / informal support that would be helpful to you?

- Not answered x12
- Free prescriptions should be available. A Blue Badge would be helpful
- Disabled parking space during flare-up
- Yes. How to cope with the depression! Why should we have to debate with GPs why some drugs are required to have a better quality of life. More support when the disease leads to a lifestyle of going to work and then going to sleep until its time for work again
- A chance to see someone with the condition before discharge from hospital
- More national awareness e.g. Media / TV programmes, radio discussions, newspapers, magazines

Experiences of hospital treatment

How do you get to your hospital appointment and how easy is this?

- By Car. Sometimes it is very difficult to find a parking place which is very perturbing during a flare up
- By Bus
- Now that I'm over 80, consultant says no need for me to continue with clinic visits
- By car. It takes approximately 20 minutes and parking is very expensive
- My wife takes me. It's ok to get there but we both have to take time off work
- I stopped having follow-ups about two years ago but up until then I received appointments by post and this worked OK
- By car. Getting there is easy as it's only 20minutes from home
- It's very easy. There is a hospital outpatient department at the local clinic
- I make my own way. It's fine
- Consultants are very good at arranging appropriate appointments. They do not have enough time to talk to you about your worries or how to be proactive about your illness
- By car. I normally drive there or get a lift from a relative. It is relatively easy. The hospital is 3 miles away. In some instances I can choose a clinic at the local hospital in Chester le Street
- By car. It's not always easy if I'm having a flare-up as I'm not feeling too well and need the toilet
- By car. I travel by car with my husband. At present we find it relatively easy
- By car. I don't have any problems as the hospital is only two miles from the house.
- By car
- By car. Later, as my condition got worse, I travelled by ambulance as I needed to be horizontal. This was later complicated by C.Diff. Now I drive
- By car. It's very easy as I only live 10 minutes away from my hospital

Is your appointment usually on time?

	Frequency	% of responses
Yes	5	29.4
No	10	58.8
Other <ul style="list-style-type: none"> • Variable • Sometimes 	2	11.8
No response	0	0.0
Total	17	100.0

How much of your day does your appointment normally take?

- Can take anything from a 30 minute delay to two hours delay but I'm not complaining as I often run over my allotted time
- Half an hour to one hour not counting prescription
- Approximately one hour
- About 2 hours. My consultant usually runs late but she is worth waiting for
- At least two hours
- Two hours
- Two and a half to four hours
- It used to take two to three hours
- Two to three hours including travel
- As much as three hours on some occasions
- Three to five hours away from work. This is time you do not get paid for
- Half a day x2
- Half a day initially. Now it takes 30 minutes
- Generally half a day off work, a 45 minute wait and 15 a minute appointment. For colonoscopy appointments take three days; one day for pre-treatment, one day for appointment, one day recovery
- Either a morning or an afternoon

How would you feel about receiving your hospital treatment at home from a nurse?

- Not bothered. I'm happy with either
- OK
- It would be nice after surgery instead of being told to go to your doctors
- Good idea. I don't like hospitals
- In my case, hospital or clinic was best
- I never thought about it as my disease is well under control. I only visit the hospital every 6 to 12 months now
- I would rather see a consultant as I am currently well but if I was unable to travel I would be happy to see a nurse
- Fine for general appointments. Not for colonoscopy / sigmoidoscopy
- I would still have to work overtime (for free) to make up my basic hours
- This would be ideal and highly desirable but is it realistic? I'm not so sure
- That's quite a good idea as it would save the worry of having to get to hospital
- I don't require treatment at the moment. My medication is regularly reviewed by my consultant
- Fine
- From a specialist nurse? Yes go for it!!
- Very happy no problem

Have you ever had to stay overnight in hospital as a result of your IBD?

	Frequency	% of responses
Yes	9	52.9
No	8	47.1
No response	0	0.0
Total	17	100.0

Was this an emergency or planned admission? (you can tick✓ more than one box)

	Frequency	% of responses
Emergency	7	41.2
Planned	0	0.0
Emergency and Planned	2	11.8
No response	8	47.0
Total	17	100.0

Which hospital were you treated at?

- Royal Victoria Infirmary (RVI) x2
- RVI until 1981 then Freeman
- Durham University Hospital x2
- Sunderland Royal Hospital
- Queen Elizabeth Hospital
- Hexham General Hospital and Wansbeck General Hospital

What kind of ward were you on? (you can tick✓ more than one box)

	Frequency	% of responses
General Medical ward	5	22.7
Surgical ward	6	27.3
Older peoples ward	1	4.5
Specialist ward	2	9.1
Other (please state)	0	0.0
No response	8	36.4
Total	22	100.0

What was your experience of being an inpatient with IBD?

- Some staff on the older peoples ward did not understand the condition and were intolerant of its effects. On the specialist ward there were no problems
- I was always well looked after
- My first experience was not good. I was told by the sister that there was nothing wrong with me and I was just constipated. But after that I have usually had good care. Apart from the morning after the operation, the assistant made me go in the shower on my own and left me to fall asleep
- It was awful as I had a ruptured bowel from a colonoscopy but the care I received was good
- When I was in hospital in 1977 for approximately three months, the general standard of treatment and general welfare was better than when I was in for bowel cancer in 2003
- It was not very good. I was in a large bay with a toilet down the corridor used by lots of patients
- Overall my experiences have been good. Sometimes I feel forgotten about, but it's usually because the nurses are looking after other patients and seem so busy. Medical wards can be difficult, especially in a bay with some difficult patients. I don't particularly like the medical wards
- Very good. Both the ward staff and my consultant's team are very sympathetic and understanding of my condition
- I was well cared for at both [hospitals]. Barrier nursing for C.Diff was lonely. But at Hexham, one felt special. The food was better at Wansbeck!

Could anything have been improved about your stay? ((you can tick✓ more than one box)

	Frequency	% of responses
No	1	3.6
Yes, more privacy	4	14.3
Yes, a more condition appropriate ward	2	7.2
Yes, more adequate toilet facilities	4	14.3
Yes, a more age appropriate ward	1	3.6
Yes, more IBD aware staff	4	14.3
Other <ul style="list-style-type: none"> • Have always found that the staff don't know anything about Crohn's • Single sex ward or single room if possible • Better food 	3	10.7
No response	9	32.1
Total	28	100.0

Experiences of medication and treatment

What type of medication do you take? (you can tick✓ more than one box)

	Frequency	% of responses
Aminosalicylates	10	23.3
Anti diarrhoeal	4	9.3
Vitamin Supplements	2	4.7
Steroids	4	9.3
Bulking Agents	2	4.7
Painkillers	3	7.0
Immunosuppressants	5	11.6
Anaemia treatments	3	6.9
Other <ul style="list-style-type: none"> • Vitamin B12 injections x2 • Laxatives x1 • Omeprazole x2 • Infliximab x2 • Osteoporosis Drugs x1 • Thiamine x1 • Calci chew x1 	10	23.3
No response	0	0.0
Total	43	100.0

Do you have any problems taking your medication? (you can tick✓ more than one box)

	Frequency	% of responses
No	9	52.9
Yes – Side Effects	2	11.8
Yes – Timing of medication <ul style="list-style-type: none"> • The drugs I take for my osteoporosis (as a result of my IBD) give oesophagitis and I have to take them half an hour before food, 	2	11.8
Yes – How I have to take it <ul style="list-style-type: none"> • Rectal treatments are painful and difficult to administer by yourself x2 • Half a day in hospital is difficult with working, this is very 8 weeks 	3	17.6
Other (please state) <ul style="list-style-type: none"> • Too little information was given to me especially when I had to take steroids. My day had to be planned around the drugs when I had to take 7 different drugs. GP/consultants refer you to 'chemists' for such advice, which I did. 	1	5.9
No response	0	0.0
Total	17	100.0

Do you take your medication as directed by your GP / consultant?

	Frequency	% of responses
Yes	13	76.5
No	0	0
Most of the time	3	17.6
No response	1	5.9
Total	17	100.0

If you do take your medication as directed, what are your reasons for this? (you can tick✓ more than one box)

	Frequency	% of responses
I have been told to take them	7	33.3
My medication keeps me well / makes me feel better	9	42.9
I know I will feel worse if I don't take it as directed	4	19.0
Other (please state)	1	4.8
Total	21	100.0

If you don't take your medication as directed, what are your reasons for this? (you can tick✓ more than one box)

	Frequency	% of responses
Side effects	0	0.0
I forget	0	0.0
Inconvenient / complicated	1	5.9
I don't think its making any difference	0	0.0
Lack of necessary privacy	0	0.0
Reacts badly with other things	0	0.0
I don't like taking medication	0	0.0
I prefer to manage my symptoms in other ways	0	0.0
Other (please state) • Had to stop taking medication when I was pregnant and breastfeeding	1	5.9
No response	15	88.2
Total	17	100.0

Have you ever spoken to your GP / consultant about any concerns you have about your medication? If so, what happened?

- I was concerned with the difficulty of administering rectal foam and was given suppositories instead. Some are hard and solid and difficult to insert even with cream or gel
- No x2
- Mostly I get the feeling my GP's do not fully understand the problems i.e.: urgency. Even though I am remarkably fit and active for my age. I still take anti diarrhoeal tablets to be confident during the day. My GP just takes my word for it
- I have terrible trouble with my joints to the point that I find it more and more difficult going up and down stairs. Nobody seems to care
- No
- Spoke to my consultant. We discussed the fact I didn't want to go back on steroids because of the side effects so we tried a different combination of drugs which appear to be working quite well at the moment. If her advice had been to take steroids, I would trust her judgement
- I always work in partnership with my consultant. I can express my concerns easily. My consultant is always informative and approachable. I don't have much contact with my GP
- I self-medicate and decide the dosage based on my judgement of severity. I generally don't have concerns unless I have a bad flare-up then ask to see the consultant for steroids
- I was referred to a pharmacist! Yet they were prescribing the drugs
- I spoke to my GP about starting a family and the effects of Infliximab. My GP didn't have any information or facts about the effects so wrote to my consultant. Again, the consultant couldn't provide any information or hard facts about the effects of Infliximab on male fertility etc. I felt a bit let down
- No but when my consultant prescribes any new treatment he always explains fully its effects and possible side effects
- When collagenous colitis raised its ugly head straight after the first course of steroids finished and GP restarted them, I asked could I not go onto a maintenance drug rather than steroids. But she said only the consultant could decide that. She has said on

many occasions that their surgery has only four patients with collagenous colitis and they don't know a great deal about it

- Yes. I felt over medicated but I am now happy that that isn't the case
- Yes. They talk to me and advise me again about how I would feel if I wanted to stop taking my pills

Is there anything that would make it easier for you to take your medication?

- No x7
- Yes, rectal treatments that are user friendly and simpler to use
- Easy swallow coatings, especially when taking large amounts of the same tablet at the same time. My azathiaprine sticks, dissolves and tastes disgusting, all four of them every day. Then I feel queasy for a short while
- If it didn't cost so much for prescriptions!
- Be given a plan / daily routine of medication to ensure we get the most benefit from the drugs
- Timing or taking it at home instead of hospital

Do you have any other comments about the care you receive for your IBD and your medication?

- No x4
- I am very satisfied
- Only that nobody seems to be bothered. GPs don't know what to do and the consultant's answer is to try this one if that one doesn't work
- Care once the diagnosis is made is generally good. However my most recent experience of hygiene and cleanliness in hospital is very poor
- The hospital care is really good and consistent. My GP is not so good. The last time I had a problem I phoned my consultant's secretary as my GP didn't know what to do and didn't want to prescribe drugs. I have now had a letter from the hospital for what to do in an emergency; what meds to try and in what order
- My GP has never been able to advise me, only request a referral to the consultant which takes time. It would be better if the GP was more informed
- The need for more specialist IBD nurses in County Durham
- My consultant is extremely good at keeping up to date with any new medication and will suggest alternatives when appropriate or asked to
- The fact that my GP, who I consider has done everything that she can to help me, but also admits she knows very little about it, makes me feel one ought to have been referred to a gastroenterologist much earlier. The hospital side of the NHS leaves a great deal to be desired
- The degree to which most [people] really cared about my wellbeing was impressive
- I feel very confident. If I need any information or am worried about anything I only have to ring and I get to speak to my nurse or consultant

Experiences of managing your IBD symptoms

Is there anything that makes your symptoms worse?

- Certain foods i.e. bread, cabbage, broccoli, cauliflower etc. looking for parking, stress and anxiety
- Certain foods
- Eating fatty foods
- Stress. Diet, mainly healthy foods!
- Bad diet. Spicy foods
- I avoid fruit, lager, wine, ice cream, anything rich
- During a flare-up: some food stuffs and stress
- Stress x2
- Alcohol
- Stress / depression. The uncertainty of the disease
- Stress at work or stress in general
- Diet, stress, alcohol
- Stress and eating certain foods
- Painkillers particularly NSAIDS / diclofenac especially. My back surgery has been cancelled because I am using steroids and can't use pain control either
- It is difficult pinpointing foods that make symptoms worse
- Over work, diet, stress, not keeping to my routine e.g.: eating at odd times of the day

How do you manage this? (you can tick✓ more than one box)

	Frequency	% of responses
Avoid things that make me worse	11	34.4
Take medication to prevent symptoms	4	12.5
Change routine to accommodate symptoms	4	12.5
I just deal with it <ul style="list-style-type: none"> • Coping strategies can lead you to lead a 'quiet existence'. Is this really that helpful? • I have turned down two offers of employment on this account. Self employment is the solution. • Rest as much as I can • Plenty of exercise: football, running, cycling etc. 	13	40.6
Other (please state)	0	0
No response	0	0.0
Total	32	100.0

Apart from your medication, is there anything that makes your symptoms better?

- No x2
- A dedicated parking space at work, a manageable routine, rest and sleep
- I always feel well when I don't eat
- Not eating
- A hot water bottle helps relieve the pain. Sometimes a warm bath seems to relax me which I think helps the pain and spasms
- Not really but I value family and friendships and I think this helps me. Having a good social network

- Generally staying fit, not being overweight and eating well. I have taken homeopathic treatments but there was no improvement or worsening of my condition
- A low residue diet
- Having a healthy diet, eating things that are easy to digest and doing exercise to help with stress
- Peace of mind and understanding from those who make the demands
- REST!!!, slowing down until my symptoms are calming down

How did you find out about the things that make your symptoms better? (you can tick✓ more than one box)

	Frequency	% of responses
By accident / trial and error	10	41.7
Support group / other people with IBD	6	25.0
GP / Consultant	3	12.5
Leaflets / Internet	2	8.3
Other (please state) <ul style="list-style-type: none"> • I believe that the medication that I take has given me my life back 	1	4.2
No response	2	8.3
Total	24	100.0

How easy do you find it to make changes to your lifestyle in order to manage your symptoms? (you can tick✓ more than one box)

	Frequency	% of responses
There isn't anything I can change	1	4.8
Easy because it keeps me well	3	14.3
Easy most of the time but sometimes I 'fall off the wagon'!	8	38.1
Difficult, but I do it anyway	2	9.5
There are things I should avoid but I enjoy them	3	14.3
I take medication to manage any problems	4	19.0
GP / Consultant	0	0
Other (please state)	0	0
No response	0	0.0
Total	21	100.0

How far would you agree that your GP or consultant treats the symptoms that are important to you?

	Frequency	% of responses
Strongly agree	8	47.1
Agree	5	29.4
Disagree	1	5.9
Strongly disagree	2	11.8
No response	1	5.9
Total	17	100.0

If you disagree with the above questions, can you give an example of how this hasn't happened?

- Can't really remember although I do think that some consultants do not listen
- I do not believe or have any confidence in my GP when dealing with any ulcerative colitis or colon cancer related issues
- All they say is 'it can be difficult'. They appear not to have sufficient time to spend with you when they tell you that you are suffering from depression

How could this be improved for you?

- It would be good to be treated as an individual rather than another person with Crohn's. We are all different
- It is difficult to say. Doctors need to be much more knowledgeable about ulcerative colitis and Crohn's disease. In my view they do not take it seriously enough
- The most significant people in my life are the IBD specialist nurse and the stoma nurse

If you are a member of a support group or organisation for IBD, has this been any help to you?

- No
- Yes
- It was very helpful, supportive and social
- Yes, I like to read about other peoples' experiences and what has helped them
- I am a relatively new member of NACC (National Association of Crohn's and Colitis) and IA (ileostomy Association), their newsletters etc are a good source of information
- Beyond any doubt. When I was first diagnosed I was clueless and had no information. I found NACC online, became a member and now I know everything I need to. The support in the early days was fantastic. I am still a member and fundraiser. I could not have coped without the group
- I belong to Crohn's and Colitis UK and although I have never had to use it, I know it is there. I feel part of it as I am a Benefits Advice Volunteer for NACC
- I have joined NACC. Hopefully such membership will be of some use
- It has been a great help. The quarterly NACC meetings provide me with a wealth of information and people to talk to about IBD
- Yes, I get the NACC newsletter and find it quite helpful
- Yes, I am a member of Hadrian group of NACC
- Yes but I haven't used them yet
- NACC leaflets and newsletters are informative and interesting
- Yes, if only by empowering me to self help and help others
- It is very, very helpful. I could not do without it. Also all staff at my clinic

Experiences of living with IBD

How does IBD affect your daily routine?

- I spend a couple of hours in the morning and the same at night to sort out my bowel habits / problems
- Generally it has no effects although I may have to cancel arranged outings, visits etc
- I prefer not to make any plans to leave my house until after 10:30am by which time I have used the loo at least three times, then taken 'stopper' tablets
- I live day-to-day. I find it difficult to make plans
- Having to go to the toilet urgently e.g. during meetings
- Some days and nights I have flare up and need to constantly use the toilet

- I don't allow it to
- When I am ill, I am unable to plan anything as the condition is so unpredictable. It can be quite isolating. I need to be very near a toilet in case of incontinence
- I know exactly where all the toilets are everywhere on my route to work and in town! Urgency to go is acute and immediate
- I have a very curtailed social routine and do not make any plans to go anywhere just in case I may be unwell. Everything has to be decided on the day
- Mainly problems with toilet habits; using the toilet 4-6 times a day can be awkward at times, especially in work hours, meetings etc
- It only affects my daily routine when I have a flare-up and I usually have to stay at home if I'm really bad
- The need to stop and rest throughout the day
- Whilst on steroids I can't have surgery for a serious disc issue or for a triple arthrodesis. I am in severe pain with both and can't take painkillers. Therefore life is extremely difficult and frustrating. I am feeling worried and depressed and until I am stable, surgery dates have been cancelled. Therefore I really could have done without collagenous colitis as well and I will have to wait for a remission or a maintenance drug
- I have good days and bad days
- During a flare up I'm twitchy and may put off appointments. If I'm not confident about the bag staying on I will postpone appointments
- I am always aware of it. If my routine is normal I can cope with it.

Is this different during periods of flare up and remission?

- During flare up I can be extreme pain and my bowel problems can consume my time until the episode stops
- Yes I would feel ill and unable to cope satisfactorily during flare up. I have no problems during remission
- During flare up I would be practically housebound
- Yes. I can lose a lot of time at work
- Worse. More regular
- Since I had an internal pouch constructed there are very few times when there is any kind of remission
- Yes it rules my life during flare-ups. Everything is a military operation planning for toilet needs
- Absolutely. During bad flare-ups one can almost be housebound. When well I love life but still have urgency when needing to use the toilet
- Yes I am significantly worse during flare-ups
- Flare-ups often come out of the blue, hence comments on making plans
- Very much so it [needing the toilet] can be as much as 10 -12 times, may be more
- Yes, when I have a flare-up I have to stay at home. When I'm in remission my daily routine is normal
- Yes. During a flare up it's impossible for me to do anything
- Flare ups come on so quickly that even when remission I worry about accidents
- It is very hard in periods of flare up. I can't go very far from my home
-

What symptoms do you find most limiting in terms of carrying out daily activities?

- Toilet requirements
- Constant pain and I won't go where there are no toilets
- Having to go to the toilet urgently - e.g. during meetings
- Having to constantly know where the nearest toilet is

- Toilet needs, especially at work where we have five staff and one toilet. But workmates are really good and now understand fully, but it is embarrassing for me!
- Incontinence if I'm not near a toilet. Tiredness both during flare-ups and when in remission
- Urgency to use the toilet and cramps are most limiting
- Upset stomach, severe stomach cramps and severe pain in my joints
- Diarrhea and stomach cramps
- Having to make sure I'm near a toilet when I've got a flare-up because I constantly need to go to the toilet
- Tiredness
- Some days I feel more tired
- FATIGUE
- Tiredness, always having to have toilet facilities at hand. I can not socialise

Are there any activities that you no longer do or are unable to do as a result of having IBD?

- No x3
- I continue to live my life as normal between flare up
- Yes just early morning i.e.: 9:30 start for walking about
- Yes. I used to be very active
- Socialising with friends is very difficult now. I can't take long journeys now unless I plan where I can go to the toilet
- Not really unless I'm having a flare-up, then I don't go racing or other outdoor activities which involve travelling distances or using portaloos
- Not currently. I have a limited amount of energy and stamina
- In flare-up times I can't be far from toilets, so hill walking stopped
- Cycling, walking, photography, visiting interesting places, church activities can be curtailed by physical difficulties and bad depression which I suffer from
- I can still do most things but not for as long such as walking and climbing
- No because I had already stopped playing golf, going to the gym etc because and of my two other issues
- Not really but locating toilets is always at the back of my mind. They seem in short supply in some areas
- Running and very soon any activity involving bending over e.g. gardening
- As long as I am in remission I'm fine, I can lead a normal life

How does this make you feel?

- It used to frighten me as I do not want to be seen as disabled. It is an embarrassing condition that you don't want to mention to others who may not understand
- Not anything much. Except people think that I am getting feeble because of my age. I do not talk about my 'failings'
- I feel like I'm constantly fighting with myself
- I feel quite depressed at times; it just makes things hard work
- Pretty angry and upset, why me? Even after 11 years I still feel angry. Some days I decide to just do whatever it is I want to do and usually regret it
- When I'm ill I just live day-to-day hoping to get well
- Frustrated, but as my flare-ups are irregular and short I know it will pass
- Very depressed and negative about myself
- Guilty as my husband is still very fit and loves walking cycling and climbing
- Fine, happy, very grateful

Please use the space below to tell us anything else you would like to share regarding living with IBD

- I just wish that the manufacturers of rectal preparations would talk to sufferers who would tell them how to make them easy and less painful to use. I have brought this up with GPs and consultants but nobody seems to know what to do about it
- Because it was 50 years ago when I started with Crohn's I now realise how much more is known and how treatment has improved. My symptoms were diarrhoea and pain and obstruction in the bowel. I did respond remarkably well to steroid treatments given when diagnosed. It took three years during which time I was in hospital four times. I had operations in 1964 and 1965. Then 1981 quite a big small bowel resection. I have had three flare ups since but they were quickly bettered with short sharp steroid treatment. I have not had flare ups for 10 years. I eat very plain foods
- There is not enough awareness. People don't know what it is. There should be more help with living allowances. After trying to apply for it, I was told there was nothing wrong with me. This upset me very much
- I have lived with IBD in the form of ulcerative colitis and then bowel cancer since 1977. It has had a fundamental effect on my life and career. I have no confidence at all in my GP dealing with or recognising the symptoms of ulcerative colitis or Crohn's disease. Only training, I guess, can improve that. In general once you have a good consultant who knows what he / she is doing, the treatment is usually good and you can have confidence in them
- Only the lack of awareness. Most people don't know the difference between IBD and IBS. I live on my own and am 40 but during a flare-up I feel very alone and so angry. The pain can be so bad I cry. Tiredness also is a huge factor; some days it's like running into a brick wall and I don't feel people understand, they just seem to think you need an early night. Some nights I finish work, have an hour's sleep on the sofa, have dinner then go to bed for eight or nine hours and don't feel any better for it. Friends think "you're boring" when you want to stop in at the weekend or you go home early. They usually say "oh come on, once you get out you will feel better" and **I don't**. Also, I am a widow and feel having IBD stops me entering into another serious relationship; the intimate side really worries me. What if I'm at his house and need the toilet in a hurry? The smells, the noise. My late husband was used to it but I developed Colitis during our marriage and didn't need to bring up the subject
- I am lucky as I have a supportive husband and friends. But IBD can be very embarrassing and socially isolating. The main feature of the condition that is overlooked is **fatigue**. Sometimes I feel as if I could sleep all day but of course I don't. I have developed osteoporosis as a result of IBD which causes me a lot of back pain. What would really help is a Blue Badge
- I can generally manage now due to remission. This seems to be down to current Infliximab treatment. Five years ago I was very depressed with my Crohn's. A subtotal colectomy followed by ileostomy left me feeling like there was no light at the end of the tunnel. Since then my life feels back on track and thanks to my consultant and the subsequent Infliximab I've now been in remission for about nearly three years now
- It's important to keep a positive outlook on life. Although I can no longer walk as far as I used to, I can still walk!! My appetite is not as good as it used to be but I still like to go out for a meal with my family. We still go dancing two to three times a week. If your friends and family know about how IBD affects your life they can be very supportive and encouraging. Having a good consultant also makes a difference
- I was expected to get three to six months at least remission after steroids. I was shocked and acutely disappointed that it came straight back. I feel I can live with

collagenous colitis but living with all three situations and in so much pain with no give and take from GP or surgeons is very hard to cope with

- There is a need to promote: 1) Research into fatigue, 2) Better treatments for burnt skin, 3) Replacing steroids, 4) Losing post steroid fat
- You must involve your family and friends. They must understand and support you with diet and the need for it. I wish people knew more about IBD. If I talk about it they think it's IBS. People feel embarrassed when you talk about it. I don't like talking about it so I keep it to myself most of the time

