

“It’s all about me”

**A research project into the role of
NACC in addressing the concerns
and needs of young people with IBD**

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“It’s all about me”: a one page summary

The people we worked with described experiences falling under **six headings**: (pages 10 – 26)

- Acceptance and coping
- Medical treatment and care
- Pregnancy
- Socialising, friendships, families
- Employment, and
- Education.
- Generally, their attitudes, experiences and ability to manage were often influenced by the **age** at which they were diagnosed.

The issues they face, which can impact at any age, are **unique to this age range** because: (pages 10-11)

- This age range is often doing things for the **first time**.
- They are more likely to **lack** life skills and confidence.
- Their **peers** similarly may not have the skills to respond and support appropriately.
- They are at an age when self-image and acceptance is already a fundamental area of doubt and **inquiry**.
- **Frequent moves** take them away from established support networks.
- This group already faces **marginalisation** by society.
- They go against the **peer norm** of confident, invulnerable and normal.

Some cultural **contexts** for NACC to be aware of are: (page 29)

- People want information but **resist signing-up** or accepting a label.
- The choice economy means a trend of “I design **a package** of what I need and who supports me”, rather than adopting one single organisation.
- Loyalty can be **fickle** amongst the sources of help available.

In **responding** to this report and this age range: (page 29)

- Trustees should know that the project was to produce a set of responses which **NACC can use** to devise specific services. The recommendations are therefore indicative of *an overall approach* for NACC.
- NACC must appear interesting and accessible to catch this age range’s **attention**.
- It must show its **understanding** of what is ‘normal’ for them.

Our main **recommendations** are: (page 30 onwards)

- NACC’s most effective long-term contribution is enabling members to manage their own condition - in other words, NACC prioritising its **facilitative and information-giving** role.
- Specifically, NACC should
 - a) build, support and make use of the **online ibdandme community**;
 - b) focus on **increasing NACC membership** amongst the 16-29 age range. NACC should act at the time of the patient’s 16th birthday, and provide a package of appropriate membership benefits.
- NACC should facilitate **support mechanisms** for this age range, in person and on-line via the NACC website.

Possible **first** steps are: (summarised on page 30)

NACC could choose to focus initial efforts on these few areas:

- Promoting Young Adult **Groups / Networks**
- Developing the on-line ibdandme **community**
- **Trialling** contact with members on their 16th birthday

Summary

Outline of the project

This project researched the concerns and needs of 16-29 year olds with colitis or Crohn's Disease, to help NACC review its services for this age range. A series of questions underpinned the research:

- What needs are felt by those aged 16-29 living with IBD?
- Is it possible to give some kind of prioritisation to those needs?
- To the extent that those needs are being met (by NACC or others), how are they being met?
- To the extent that those needs are unmet, how could NACC contribute to meeting them?

As well as generating answers to those questions, the project clearly tapped a need amongst those we were in contact with. We know this not just by the numbers of people who responded, but also by the depth from which their responses came and the honesty with which they engaged with each other and ourselves. We are deeply indebted to all participants.

Despite the support offered on-line and through organisations such as NACC, CICRA and the IBD Club, the project still reached people who had never met anyone else their age with IBD.

Our title, "It's all about me", could be taken as a typical self-absorbed 16-29 year-old lost in their own experience as they struggle with finding their place in the world. In fact, a newly diagnosed participant said it. In her focus group she had several confrontations with another participant diagnosed many years previously. At the end, she acknowledged the help she'd had in meeting him, saying it had been helpful "getting it in perspective, it's all about me".

By "It's all about me" she meant that managing her IBD was all about how she responded – and, that her response was *up to her*. It is that self-aware, 'in charge of my own destiny' attitude that we feel best helps people cope with their disease, and which NACC can help people in this age range attain for themselves.

Overview of recommendations

Having seen first hand young people grappling with their life circumstances, we are convinced that NACC's most effective long-term contribution is enabling members to manage their own condition - in other words, NACC prioritising its facilitative and information-giving role. This age range are on the move in their lives. NACC can help them in pressing forward on the journey.

Through the web forum, the project has resulted in a thriving self-supporting ibdandme community. NACC can use this community as a platform for the future.

Our recommendations, set out on pages 29-36, are thus directed towards two key ends:

- To build, support and make use of this community.
- To increase NACC membership amongst the 16-29 age range.

In terms of increasing NACC membership, we suggest two approaches: First, making use of the patient's 16th birthday (where a relative joins on their behalf), and second providing a package of appropriate membership benefits which can be promoted generally to this age range.

We encourage NACC to facilitate support mechanisms for this age range: First, by creating opportunities for contact in person, such as through further work on local Young Adult Groups, creating a young person-aspect to NACC-in-Contact, and through buddying or mentoring. And second, by contact on-line through the NACC website.

We also encourage more information on day-do-day living (as opposed to 'technical' information about medication and disease management.

How the recommendations can be taken forward

The project was intended to produce set of responses and ideas which NACC can use to devise specific services, activities or publications.

Our recommendations are therefore indicative of an overall approach for NACC rather than a prescriptive list – Trustees may find it preferable to see them as Areas for Action rather than recommendations. Some recommendations may echo or overlap work already in progress.

As trailed in the original brief, this project may trigger a review of how NACC works with this age-group, given that current frameworks have not to date created long-term NACC support networks for this age-range. In making recommendations, therefore, our hope is to generate further momentum in NACC for its engagement with the 16-29 age range – engagement which has already taken place within this project, and which we have been privileged to be part of.

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Methodology

The process in detail

The project got underway in the autumn of 2005 with a news item in NACC News. At the same time the www.nacc.org.uk/ibdandme webpage was set up, inviting people to register their interest in taking part in the project. We also wrote to all the IBD nurses on NACC's database, to target IBD patients who might not be members of NACC. The webpage, flyer and poster used a logo and artwork specially designed for the project.

Registrations flooded in, and Katie in particular fielded many phone and e-mail conversations with those registering or enquiring about the project. It quickly became clear that we had enough participants to run the focus groups. We also learnt how open people were to sharing their experience with strangers.

Based on those first registrations, we chose Leeds and the topic of Employment for our pilot group in December 2005. In January 2006, we promoted a further six groups around the UK. We needed to meet the needs of all participants and also important to separate and focus on particular areas of inquiry. Accordingly, the first half of each group explored an initial theme set by ourselves based on responses to the web registrations; the second half created space for all other issues of importance to the participants to surface. We shared the facilitation and note-taking between us.

We made time after each group to review the session and draw wider lessons not reflected in the discussions or flipcharts. We particularly valued that first ten minutes or so after everyone had left, and we were left alone with the evaluation sheets and flipcharts and the sense of 'what have we all just created over the last three hours?' The resulting discussions informed how the next focus group would be facilitated – in terms of process and in the questions we would ask.

We also had regular in-between-groups telephone conversations to plan up-coming groups and collate findings.

In all, we held seven focus groups:

Date	Location	Initial theme:
December 2005	Leeds	Employment
18 February 2006	Glasgow	Socialising and making long-term relationships
4 March 2006	Bristol	Identity, self-image, impact of diagnosis
11 March 2006	Central London	Socialising and making long-term relationships

11 March 2006	Central London	Education (covering from sixth-form to post-graduate & other adult education)
1 April 2006	Nottingham	Medical care and treatment, and communication with medical staff
8 April 2006	Manchester	Family relationships, leaving home, support issues

Focus group participants facts and figures:

- Total number of participants: 37, including one non-ibd partner.
- Male: 7; Female: 30.
- Average participants per focus group: 5.28 people. The smallest group involved three participants, the largest involved nine.
- Ethnicity: 33 White Caucasian; 4 from BME communities.
- Average age when symptoms began: 16.74.
- Average age at diagnosis: 18.47.
- Average age now: 23.65.
- Youngest recorded age when symptoms began: 3.
- Youngest recorded age at diagnosis: 9.
- Average number of years between when symptoms began and diagnosis: 3.35 years.
- Biggest gap between when symptoms began and diagnosis: 9 years, for a teenager then aged 14 and now aged 26.
- Average number of years between diagnosis and age now: 5.17 years.
- Smallest gap between diagnosis and age now: about seven months.
- Biggest gap between diagnosis and age now: 15 years (for a participant now aged 25).

We started formally recording data as to age at onset and diagnosis after the earlier groups, when the significance of 'age at diagnosis' became apparent. The above statistics are therefore from the last four groups, or 23 participants.

After the last focus group, we brought our findings together to produce seven key areas of enquiry. We then used a web discussion forum to generate further discussions on our key areas of enquiry. The forum also gave those too ill or too far from a focus group a chance to take part in the project. The forum was planned to run for a fortnight, but in response to participant requests NACC graciously made the forum open-ended pending a formal trustees' review of the project ¹.

There was enormous activity on the forum within the first two weeks, and by July 2006 there were about ten postings a day on average. The forum quickly developed additional participant-led discussion strands. We moderated the forum for acceptable language. We made some postings in the first fortnight, but thereafter let the forum follow its own energy in providing support and information to its members.

¹ The forum is still active and can be found at <http://www.ibdandme.nacc.org.uk/>

Three of the discussions we introduced initially – “Three years to acceptance?”, “Tackling the medics”, and “(Not) going to your local group” featured in the seven most active strands, along with the participant-introduced topics “Introductions”, “Cool site!”, and on prednisolone side effects and a diet sheet.

In July we used the web forum again to test some of our main conclusions and findings, as part of finalising this report.

At the time of this report:

- The ibdandme website had received 8,558 hits, with approx 330 people registering from the UK and other countries including Canada, Belgium, Iran and Malaysia. Their diagnoses are: CD 202; UC 127; uncertain diagnosis 19 (respondents could tick more than one option).
- The web forum had attracted 263 members, who produced 145 separate discussion topics and in total posted 983 individual messages. 33 users registered and then never logged on, and a further 46 logged on only once. The three most active users logged on 311, 261 and 204 times respectively. Statistically, each user logged on to the forum an average of ten times.²

The project was overseen by a Working Group involving the two of us, Richard Driscoll, John Clarke and subsequently Elaine Steven. The group met three times in June and December 2005 and May 2006, and commented helpfully on our feedback about the process and our findings. The group also received a draft of this report.

Our reflections on the process

Particularly within the focus groups, we were informed, energised and moved by the contributions people made. People demonstrated great willingness to share intimate experiences, both practical and emotional. We were both at risk of being ‘hooked’ into our own personal experiences, so having both of us there was an important safety net. One participant needed individual private support at one point.

After the Leeds pilot (ten confirmed participants the night before, only three turning up), we modified the process to keep in greater and more regular contact with those booking to take part in a group. This helped increase participant numbers, but despite keeping in last-minute contact with those signed up to come we still experienced an average of about 40% drop out. Greater numbers would have provided more validation of the data, but over the whole seven groups we feel we provided enough space for the key issues to arise.

Some participants indicated in the feedback that they wanted handouts, or signposting to resources, or even an IBD nurse or gastro consultant to

² These web-based structures were critical to the project’s success, and we are particularly grateful to NACC trustee and webmanager Nigel Westwood for his creativity and support.

have been present. We saw this feedback positively, showing that people really got into their experience. In other words, they lost sight of this being a research project; and, that they were desperate for information.

Just as for the focus groups, the web forum similarly proved to be a moving experience for us. Many postings thanked NACC for making the forum available; clearly, some of the project's participants had not previously made use of other existing IBD-related discussion boards.

Web forum users responded with great speed and sensitivity to each others' fears and questions, reinforcing our finding from the groups that for this age range, peer contact – in whatever format – offers one of the most valued forms of support.

Evidence

Introduction

Almost all groups highlighted:

- The difficulty of talking about the condition, whether to friends, family, potential partners, employers, colleagues.
- For those diagnosed as an adult, the frustration of 'no longer being able to do what I want to do'
- A process involving diagnosis, low self-esteem, poor self-image or body-image, denial, anger and acceptance
- The lack of public awareness, and it being an invisible disease
- A split between those who primarily sought (and got comfort from) detailed information about the condition and medication, and those who wanted help in living day to day
- Fears about long-term effects of medication especially steroids and azathioprine, and of surgery
- Fears about pregnancy: getting pregnant, flare-up during pregnancy, risk of transmission to children, children having to look after the parent.

Many of these issues affect an IBD patient of any age. We are therefore most interested in what makes their experience **unique** or different to other age ranges? In other words, what is it about being 16-29 *and* having IBD that defines and shapes their needs?

Some answers so far to these questions:

- People in this age range are often doing things for the **first time** – disclosure, seeking employment, managing the condition, exploring relationships and sexuality.
- Being younger, they are more likely to lack the **life skills** and confidence to enable them to do these first-time things well. Feeling tired and unwell further affects their ability to cope and to feel self-confident.
- At this age, self-confidence and a positive self-image may depend more on what **other people** think of them than what they think of themselves. Comfort thus depends on external not internal reassurance, which a peer group may be unwilling or even unable to provide because of their own lack of life skills and awareness. The embarrassing nature of the disease and its symptoms exaggerates these difficulties.
- IBD – like any other chronic condition – affects self-image at an age when identity is already a fundamental area of inquiry and doubt. This makes the journey to inner **acceptance** of the disease, and thus greater self-confidence and self-esteem, even more turbulent.
- It is common between 16 and 29 to change address several times. For IBD patients this means moving away from established support

structures (typically family and friends) and from medics who know them and their condition. Family support structures may already be **under strain** for reasons not related to the IBD.

- Society has a habit of disregarding or patronising young people. Being 16-29 *and* having IBD risks further **marginalisation**: its symptoms create additional barriers to seeking care, support, information and acceptance. It can also make this age range wary of systems (such as the medical profession) and organisations (such as NACC).
- Particularly at the younger end of the age range, often the paramount concern is to match the **cultural norm** - confident, invulnerable, and *normal*. IBD contradicts this cultural norm in virtually every respect.

We have identified seven areas of evidence within this report: age at diagnosis; acceptance and coping; medical treatment and care; pregnancy; socialising, friendship, families; employment; and education.

The first specific area of evidence, the age of participants at diagnosis compared to their age when taking part in project, does not so much inform NACC services, but is vital information to appreciate how participants interpret their subsequent experience. For the remaining six areas, we provide information under the standard headings: "What people told us:", "This area is important because:", and "People wanted:".

All our recommendations for NACC arising from this evidence are contained within the final Recommendations section.

Age at diagnosis

We quickly came to notice that age at diagnosis was an important context within which our participants – average age at diagnosis 18.47 years old, seven diagnosed under 16 – framed their experience.

Generally, we found that participants diagnosed in childhood showed a much greater acceptance of their disease and a much more positive attitude to life. They have had a much longer time to internalise the 'new' reality; and they generally felt the illness had had a less significant impact.

The following contrasting comments are from participants diagnosed in childhood (speaking first) compared to a more recently diagnosed participant:

"How could it have had an impact on me? It had a huge impact on my parents, but not on me", versus "[I'm] very emotional. Everything starts me off, is it the illness or the medication, I don't know."

Likewise:

"I don't care about it, it gives me motivation" versus "I'm not very accepting of it, I know it would be better if I'm more accepting but I'm not."

And this exchange in a focus group between a 'childhood' and a 'diagnosed post-16' participant:

"After a few years you've got to get on with it."

"But I don't want to get on with it. I try not to think about it."

Our most vocal childhood sufferer said:

"Whole thing in relative to my life, it's not so big. I don't talk to people about it, they really don't give a shit. Yes it was difficult horrid at the time, it was absolutely horrendous at the time. After the first ten years, there was no point in dwelling on it, don't want to waste time."³

Parents can unwittingly contribute to fostering a lack of self-responsibility in their children: the EPP Children and Young People self-management pilot courses found that in caring for their child's condition, parents may also reclaim authority in areas of the child's life not directly affected by the condition.

One ibdandme participant said "[It's an issue] taking responsibility for managing the disease, especially if you were diagnosed as a child and your parents did it all for you. It was a real shock when I had to pay for my first prescription."

In this sense, reaching the age of 16 or 18 for some felt like being diagnosed a second time, because of the reorientation needed to manage the disease. Further, patients may not know very much about the disease because up to now their parents have held all the knowledge in the family.

For those diagnosed in childhood, after getting used to the medical and lifestyle implications, there was the delight of discovering greater and greater freedom – a growing confidence in managing the disease, joining with being of an age and maturity to be able to do one's own thing. One said: *"You get more immature as you grow older!"*, meaning at last they could do the things other young people had already done years before them. Some described this as being like a late teenage rebellion – it was their first chance to rebel against the disease by not taking medication, or attending appointments, or being careful about what they eat.

"I know that eating the wrong thing causes problems but it still doesn't stop me. Knowledge isn't enough [to affect my behaviour]."

For those diagnosed from 16 onwards, however, the feeling was of resentment and frustration:

"Going from being able to do whatever I wanted whenever with whoever, to being very restricted."

No recommendations flow directly from our exploration of the impact of age at diagnosis, other than in connection with recommending buddies, befriends or mentors or seeking people to talk about their day-to-day experience, (page 33). In our experience, those diagnosed the longest may have the most reflective responses to offer.

³ See the later section on Acceptance and Coping for how participants managed the journey from denial to acceptance.

Acceptance and coping

This section of evidence is fundamental to understanding how people in this age range manage their illness. Participants showed themselves to be at all stages of denial, anger, exploration and acceptance. It has been a rocky road for several of them, and not always a journey of forward progress.

What people told us:

"On diagnosis, your instinct for coping kicks in. But then you think, 'this really sucks', you've got it for however long."

"All that's on my mind at 18 is jeez this is gonna be with me for the rest of my life, ok, so what do I do when I start uni, start work, start a family....?"

"Very emotional. Everything starts me off, is it the illness or the medication, I don't know."

It's clear then that some experience a time of disorientation on diagnosis, in which fears about the future are mingled with managing the immediate impact. The circumstance of being 16-29 does have a big impact on these journeys to acceptance:

"As a teenager you've got a crap self image anyway, steroids blow you up like a balloon and you don't want your mother telling your friends about your bowel movements."

"16-24 yr olds perhaps have the main stress of trying to launch ourselves into our lives, uni, work, family etc. it's a huge time of change so maybe more support in dealing with the future is needed, how to deal with the illness in a work environment and such."

"Teenage years were hard enough self image wise without CD and steroids."

"With the ups and downs of CD, it's hard how to see the rest of my life, long term plans, what kind of help might I need. It's just a big question mark."

"I know as much as I want to know about the medical side, not necessarily as much as I need to know, but what I need and put value on is support and learning how to cope."

For most, time provides the best means of becoming more accepting:

"You're disadvantaged as a teenager; everything is going on for you at that time. The first two years are spent getting your head round it. Then you begin to be able to manage it, and then other things creep out."

"For me, it took about three years to get to emotional stability."

"You learn that you can still do what you want to do."

Some found inner resources to move themselves forward:

"IBD doesn't have to be a negative, sometimes you can turn it into a positive, like having a more laidback point of view of life."

*"Anger and Why me? Then I pulled myself together."
"It gives you a drive to do things and succeed."
"Being strong used to mean not telling anyone, not dealing with it, ignoring it. Then I realised I wasn't accepting it, I was pushing it away."*

Many found contact with their IBD peers helpful. Feedback from the focus groups as to the key message from the day always included comments such as 'You're not alone', "there's hope of help", and "learning about other people's experiences of CD and UC who are of a similar age."

"Contact with people who are of a similar age and are at the same kind of stage in life is so helpful, and stops me thinking I'm going to get dismissed as just being silly if I've got worries about something, or just need to vent my emotions."

"Hearing from [another participant] has been helpful, getting it in perspective; it's all about me." [meaning, it's up to me how I respond]

And the view from the other side of acceptance?

"My Crohn's Disease never plays a factor in my decisions, which may or may not be a good thing – it's about being independent."

"You can't control your illness. Therefore the things you can control, you have more determination to take control."

Three participants who had a 'can do' attitude about their IBD were asked what was the trigger point of shifting from an earlier 'can't do' attitude? For two, it was being told that they shouldn't try to achieve academically, but should let the disease restrict them. For the third, it was seeing someone else in a much worse condition and thought 'that's not how I'm going to be like'. In other words, there was an inner realisation in response to an external challenge or possibility.

We tested this 'trigger moment' with web forum participants, and these are some of the responses:

"I still cry sometimes, but I think I've done very well at accepting it and dealing with it, though I don't think there was a 'trigger', just living with it over time and realising that you can live with it. It's hard sometimes, I'm only starting to improve now a year after I started getting sick, but I know that I will improve, it won't rule my life."

"I was such a compliant child by nature, that I never really thought to rebel against the diagnosis itself, or the medication. I think it only really hit me a couple of years ago to be truly angry and disappointed, and that was because I was beginning to realise that I could potentially do/have what other people my age did, and so I sort of woke up to what I saw as the obstacle. So...actually I'm describing the 'trigger moment' thing in reverse, but anyway, that's my story."

"Like many of you, I seem to change from accepting it at times and finding it more difficult at others. I think when I first found out I had Crohn's I didn't really deal with my feelings about it properly, I just thought, 'right, that's it, let's get on with it' ... [but following a bad flare-up], I think now that I have become more open and honest with myself about the way I am feeling as well as with others, I have accepted the Crohn's and all the things that come with it more."

And some participants are still on the journey:

"i was diagnosed when i was 16 and am now 23 and i havent really ever come to terms with my uc ... i feel like if i'm not better i'm letting every one down and if i'm taking medicine then i'm ill and its like a big cycle. i know its stupid and i dont understand why i feel like this and i dont know how to stop."

Finally, one participant drew some wider lessons from their experience:

"I feel a big help would be to encourage people to use their own initiative to look at what their disease is, how it works... then you can go in to see consultant etc knowing more about a disease and being able to feel comfortable talking with professionals about your condition or even talking to other people. If NACC could educate people to take some responsibility themselves about their condition then I feel it would encourage people to be more open and confident about talking about their condition."

The themed session on "Identity, self-image and the impact of diagnosis" identified the following priorities:

- Impact on family, parents, partners***⁴
- Adapting to the physical symptoms***
- Doing the things I want to do***
- The experience of getting diagnosed (from onset to diagnosis)**
- Acceptance – adapting mentally to the diagnosis**
- Impact on employment**
- Impact on friends*
- Managing the medical profession*
- Managing medication

The resources participants had turned to included counselling, NACC in Contact, NACC booklets (*"but they become a bit basic"*), reading about others' experiences in NACC News, and also being a participant in an ibdandme focus group.

This area is important because:

Ultimately, it is up to each individual patient to manage themselves and their disease. Most people seemed to reach stability by facing it to the point where it is 'just' a part of me. It is important to be able to appreciate how well you're handling it and what to do with it: some participants commented on their pride in managing the disease successfully. It enabled them to take a step back and have a rational or real perspective of it and its effects.

Women formed the large majority of our participants: 80% of ibdandme website registrations, and 4:1 at the focus groups. We have no statistical evidence that men find it harder to manage the emotional consequences of diagnosis, although we are aware of much generic research evidence that statistically shows men delaying seeking medical help and in being

⁴ As ranked by focus group participants, *** being the most important.

proactive about their health. Our women participants certainly thought that this was the case!, and we infer a male reluctance to tackle these issues given that comparatively few men volunteered to take part. This area may be a future research topic for NACC as it looks to promote support for people in this age range with CD or UC.

The passage of time, for some, and 'trigger moments' for others, point to important support opportunities which NACC can provide. Time cannot be speeded up, nor is it appropriate to instigate potential triggers; but contact with other patients of a similar age frequently emerged as one of the best ways of navigating the internal journey towards acceptance and self-management. Understanding these issues may also be of help to NACC in Contacts, parents and the medical profession.

People wanted:

- Making a link between diagnosis and getting information – a 'bounty pack' for IBD.
- A simpler-structured and more informative website ("drop-down menus are too long"; "website doesn't tell me anything I don't know")
- More positive case histories
- Close network of support
- Reduced-fee counselling
- A "These are the facts" card for giving to people, like the "Can't Wait" card
- Represent young people in the publicity, to counteract perception that "people think it's an old people's disease."
- Give young people access to the reality of the disease, how others live with it and how others build their lives around it.
- Literature in 'their' language ("*All of these things are hard to come by and often are written in a way that only the over 50's can understand or often it is only relevant to the over 50's.*")
- Contact with their IBD peers
- Preference for in-depth personalised information ie not just through general info sheets, but eg via mentor, buddy etc

Medical treatment and care

What people told us:

Participants ranged from:

- being passive in the hands of their specialist:
"*No-one's ever offered me a choice of what to take*"; to
- challenging the attitudes they find:
"*I insist on asking all my questions before I leave. He didn't understand why I wanted to know what was going on*"; to
- reaching a collaborative relationship:
"*My consultant writes me a list of things I could do/medications I could take. I go away and research them and then decide what I do.*"

Some participants couldn't praise their medical team enough; many, however, reported negative experiences. What stood out was the inability of some participants to assert themselves:

"I can comment on my symptoms to my consultant, but I don't feel enough power, I'm helpless in the face of my consultant whom I see every six months."

"I feel my consultant makes me feel stupid, that my symptoms don't exist or that they're not significant."

"Medication is never long term it's never 'this is how you're going to be in the future'. I'm still on the same medication from years ago. I don't know where I'm heading."

Participants had standard difficulties in getting enough time during outpatient appointments, and managing the outpatient appointment system. Two participants felt that only when their symptoms were more serious did the medics get *"more aware, take more notice, there's more evidence that you're actually ill."*

More specific to this age range, however, were the difficulties caused by the many changes of address typical for this age range. *"I've had to switch my GP so many times, university, home, London";* and another: *"It's worth it to travel 2 hours to the hospital in order to keep the same specialist team."*

More positively, one participant told how she was given an appointment for one month after her diagnosis: *"I had 25 minutes with the consultant and the IBD nurse, very positive discussion not just about UC."*

This is just what others would have liked, as few patients are able to ask all the necessary questions at the same time as digesting their diagnosis. *"Not when you've just been told, [but] a day later or a week. And not ideally to ask the doctor, but rather an IBD nurse or anyone who understands what it means or is living with it, and who can give advice about how you tell people at work, how I can ask my doctor questions etc"*

A clear message was that patients can still be proactive in the face of professional busyness or disinterest. Several forum postings said that if you initiate interest in your treatment or medication, doctors tend to respond in return by being interested, and the quality of the experience for the patient increases.

"The problem is sometimes that they see a lot of people, some people take an interest in their disease and other don't. I have done lots of reading up on mine and looked in to the medication side effects etc myself, I found that once I showed to my consultant that I was interested in my condition that they were much more approachable."

"When it comes to making the decisions about treatment, I feel that I am always allowed to have my say, my doctor is usually willing to give it a go. I think that his approach is brilliant (especially for younger people) as it gets them more involved and helps them understand that this illness is for life and is their responsibility."

We didn't focus many questions on transition to adult care, and the evidence that emerged was patchy. One participant spoke of the stress on the parents at transition; another, that her adolescent stunted growth was not picked up by the adult team. One participant had advice for managing the transition:

"I think that its a good idea to keep the child with the paediatric gastroenterologist until the child has had a few visits with the adult gastroenterologist and feels happy and confident that they will be well looked after."

One forum participant made an important link between proactive patients and transition:

I just feel that if dr's and ibd nurses made children aware of how they can help themselves and look after their illness, it would make things a lot easier for both the medical team and the sufferers themselves. Also in the long term make it easier for children to be transferred to an adult hospital, as they will be able to inform the Dr of their previous treatments but also tell the Dr what they feel works for them.

This area is important because:

This area links many aspects of the ibdandme project: young people's more or less positive encounters with structures and adults; the scope for self-management; and the impact of limited life skills and of self-confidence impaired through ill-health. This is especially true for patients managing the system without the active participation of parents. Health professionals need to be very skilled to respond appropriately to a young person's emotions when communicating diagnosis.

We also suspect that patients may need support and information to realise when they are not happy with their treatment and care, to be able to investigate and research it, and then challenge the specialist.

People wanted:

- Having supportive family and friends ***
- Access to IBD nurse **
- Being involved in decisions on treatment/ care **
- Clear relevant information about the condition at diagnosis *
- Understanding employer / school/ universities *
- Information about living day to day
- Time to discuss when diagnosed
- Having a GP who knows about IBD
- Better communication / transfer of information from specialist and GP

Participants also mentioned:

- A session on diagnosis, and then a few days later with the nurse to talk about the diagnosis in more detail, emotional stuff, introduce NACC
- Bounty pack/automatically mention NACC on diagnosis

- Being on a gastro not general surgical ward
- Information about side effects and long-term effects of medication, particularly steroids and azathioprine
- Advice about food
- Advice about complementary therapies
- Access to nutritionist dietician
- Consistent support from hospital teams

Pregnancy

Concerns about pregnancy featured as a high concern for several (usually female) participants. They expressed doubts about:

- their health and its impact on getting pregnant and during the pregnancy
- whether previous surgery had reduced the likelihood of safe conception and pregnancy
- medications affecting fertility
- fear of an early menopause
- the difficulty in absorbing the pill and thus needing to take additional contraceptive precautions
- remaining healthy during the pregnancy
- passing on IBD to children
- being able to parent effectively whilst having a flare up.

One participant listed her concerns and then said *"These are the things I don't ask my consultant. They're on my list but it never gets asked."* Another: *"I've never had nine months of well-ness so how can I choose pregnancy?"*

These doubts prevented some women from taking any steps forward – they were either stuck about seeking information from their consultant or elsewhere, or stuck about taking appropriate steps to be ready to try and get pregnant. In other words, the possibility of finding reassuring information was not enough to overcome the fear of receiving potentially devastating news.

"I'm in a catch 22 [about pregnancy], I want to know more but I don't want to know."

"I'm 22, friends are married with children, how do I explain to a potential boyfriend? The likelihood in my family is my children will have it too. If I have kids, I've imposed it on them. If I get worse, will they end up looking after me?"

One participant said that she *"didn't find NACC sheet helpful – too general, no information about whether you fitted into the 'most people will be fine' group."*

It's important because:

Women wanting to have children, whether 16-29 age range or older, can feel as though everyone else in their peer group has small children or is pregnant. Along with the difficulties of finding a sympathetic partner (for those not wanting to remain single) are added the peer pressure from healthy friends.

The fears about pregnancy stopped some women from even finding out whether or not they might have any problems. They were – perhaps needlessly - delaying having children because of their IBD.

People wanted:

- More specific information about medication and surgery and their implications for conceiving and pregnancy
- Advice on maintaining health during pregnancy

Socialising, friendships, families

What people told us:

People encountered difficulties for two main reasons.

First, they felt unable to socialise in the same way as their friends did. They couldn't manage the frequency, the late nights, the lack of poor standard of toilets (meeting new people means going to unfamiliar new places), and that socialising often involves alcohol and spicy food, pizzas or other 'difficult' foods.

Second, socialising is harder because of friends' expectations not being met, and thus a fear of becoming unsociable and not even being asked. *"I was gutted because I wasn't invited to something, even though both they and I knew I couldn't have gone".*

Add in the peer pressure of *"Most people in my life are really healthy, successful, active. They try to be understanding about me"*, as well as those diagnosed recently who mourn their former partying: the result is that for some participants a normal social life began to feel like an unattainable dream.

Both these reasons contributed to guilt about being able to socialise, especially if for one who said:

"Falling asleep at 8.30/9.00pm – I fear the impact on my partner, another early night".

Some participants internalised this guilt or frustration into a poorer self-image:

"Being exhausted drains me of my humour and my personality and not feeling like me makes me feel awful it slows my brain down."

There were positive experiences: *"There are people who you'd never be as close to without having CD"*; and those participants who said, *"You really get to know who your friends are"* – meaning that they were left with a smaller but truer circle of support.

People also generally welcomed their friends' interest in the disease, but only up to a point.

"The more it's talked about the less of a taboo there is but it is still a really personal thing that you don't want everyone discussing."

"It's such a huge thing in your life but you want it to be small."

Some participants were selective in who they talked to in detail about their ongoing health – reserving one or two friends who heard everything, and keeping a more superficial "I'm OK thanks" for others.

An enhanced difficulty for people this age is that their peers may lack the emotional competence or maturity to respond appropriately. Participants described themselves as having to manage their friends' reactions as well as their own:

"The dilemma is, I want friends to be aware but I don't want them to talk about my bowels."

"It's like teaching, you have to choose how you tell them, and you have to change what you say depending on their reaction."

"You put a lot of burden on yourself."

"You don't need to validate your experience by having people treat you specially or seriously. You don't want either a giggle or 'oh my God' in response when you tell people."

"Each time I have a flare-up my boyfriend leaves me. They just can't cope with it."

Sadly, NACC local groups rarely featured as a support structure. Some people have tried them:

"I went to a meeting when I was first diagnosed 4 years ago. I was so disappointed as I was 20 at the time and the average age of the 15 or so people there was 60!!"

"I have been once, and there was only one person within 30 years of my age group... not fun!!".

Others are blocked by their fears even to turn up:

"To be honest I have always wanted to go to a meeting with other people of my generation but I am worried that these NACC meets are older people who perhaps just want to moan about life and IBD (sorry if I'm wrong) but I would rather just speak to people and make friends of my age group who know what I cope with!"

One group has tried a different tack. A member wrote:

"We do, however, having something called NACC Friends where we arrange an evening to go out and have fun and talk or not talk about IBDs. This is open to everyone in our local area including friends and

families of those with IBDs. There is no age limit on these evenings, just the requisite that you are young at heart."

These meetings take place about four times a year, which she admitted were not frequent enough but is all they are able to organise.

Another 'tried-it-once' participant was galvanised into action:

"I'm working closely with the Gastro nurse to try and encourage younger non NACC members to come along to our first meeting next week. I'm hoping to arrange some fun events like a quiz night, bowling etc."

Speaking positively about her local group, one participant said

"Intrigued by the information provided by my local group, I ventured to a group meeting a year ago (I was 21). I had only been diagnosed with UC a couple of months previous so was keen to meet to people in a similar situation and listen to any advice. Everyone was lovely and made me feel very welcome, though I was the only person there under 40 ... so I think they felt bit sorry for me."

One participant neatly summed up the difficulty:

"Older people love to talk about how ill they are. Younger people don't!"

She meant, we want to talk about everything except how ill we are.

We heard an interesting parallel experience from the stoma world:

"This year I was invited to an open day for 'Ostomates' which was organised by my Stoma Clinic. I thought this would be a fantastic opportunity to go and chat to others of my age and speak to suppliers about appliances etc. How wrong I was! My friend came with me (also with stoma) and we left after about 20 minutes feeling very fed up and angry. The fact it was full of over 70's we could just about handle, but the attitude from the supply companies was unbelievable - no one took us seriously and one of them ignored us. All of their literature is focused towards 'older' people and so are the appliances and clothes."

Note the positives that encouraged these two people to turn up in the first place: a chance to meet other people, hosted by the hospital, at an event related to their specific medical circumstances.

Exploring family relationships inevitably led to a wide range of participant experiences. For some their family – or specific members of their family – were the only ones they could talk to; for others, they were to be shielded from the worst of the disease. Some families grew together through the experience; for others it was a further cause of friction.

- *I was still at school when I was diagnosed, and I was thinking I don't want to tell my mum and I don't want to tell my friends.*
- *My mum was a nightmare – mothered me so much*
- *My mother blamed herself for my CD*
- *I censor what I tell my parents*
- *My CD has brought my family closer together, I've been on a traumatic journey and they've all come through it*
- *My grandfather has CD. Me having it too has helped me to get to know my grandfather better, and my father to know his father better too*

- *My sister asks my mum about me and tells her not to tell me she asked (she doesn't want me to know she cares!)*
- *My boyfriend understands but he doesn't like to talk about it*
- *I feel more secure with my parents [than my boyfriend]*
- *I feel sorry for my mum, because she's ill herself*
- *All the worry comes externally. You get yourself sorted and then someone else comes along worrying*

For all participants, the IBD is imported into an already complex web of family history and relationships – and is thus generally not bracketed off and treated differently from other family 'issues'. What's clear is that for some people the family failed to be the source of support that it could have been.

The specific focus group on relationships identified issues in relation to socialising, building long-term relationships, and issues with the family.

These were prioritised by the group as:

- Managing your feelings responses to your CD***
- Fear of impact of CD on your partner/ the relationship***
- Other peoples lack of awareness or understanding**
- Feeling different from others my age**
- Appearing well feeling ill**
- Managing other peoples response to your CD*
- Sense of identity as a 16-29 year old*
- Cancelling leaving early being a burden
- Choosing who / how to tell
- Impact on relationships with parents

The themed focus group on Socialising produced the following list of priorities:

- Feeling different from others my age***
- Managing urgency***
- Anxiety about when to have that conversation**
- Finding out which foods not to eat**
- Managing other peoples responses*
- Feeling like a burden to others*
- Others lack of understanding*
- Impact on the spontaneity of socialising
- Impact on relationships with my family

And in the focus group on family relationships, and leaving home, participants' concerns crystallised around treatment & care; impact on family relationships, and leaving home and choosing where to go. These were prioritised as:

- Being in control of who knows what friends/family***
- Having a supportive employer / university***
- Access to time with IBD nurse or other medical expert**
- Better hospital experiences (ward colleagues, food, treatment, staff attitudes)**
- Coping techniques for living day to day/ stress*

- Getting through exams / study
- Confronting / facing up to medical system / staff
- Information about IBD for your family
- Medical technical information about IBD

This area is important because:

Socialising and friendships play a very large part for people in this age range. Away from the restrictions of home, one's peer group offers a place of freedom to discover new attitudes, new interests and new identities. It is all the more devastating, therefore, to find access to this place restricted by CD or UC.

Inevitably, each person is very different in how they want others to respond; hence our emphasis on the importance of each individual being able to manage themselves in talking about the condition. Uncertainty in talking about oneself is aggravated for this age range by the risk that one's peers may not be able to cope with the illness. Your life changes; and if friends aren't around to see that all the time, they may just see you retreating into your shell. It's hard not to take personally any rejection from your friends.

It was interesting therefore to see the specific strategy of separating support networks. We interpreted this as splitting off and 'hiding' the negative by going to the same person each time they're ill, and maintaining a positive front for others. Participants were thus consciously managing their emotional relationships and who they disclose to, and creating different types of relationships to help them cope.

People wanted:

- Knowing where there are clean public toilets
- Support mentor programme for those with IBD
- Counselling emotional help
- More information about what help is available
- Neutral person to talk to
- The chance to socialise with peers (and thus at a place with good toilets and an event not focussed around food, drink or late nights)
- Not replicating a passive 'support group' style
- Something based at the hospital – local NACC group could support it to reach other young people
- Actual (not on-line) young people groups
- Way of putting in touch with others in your area – regional database
- Information for siblings
- Leaflet on 'How to do a good hospital visit'

Employment

What people told us:

Participants found difficulties when seeking employment and whilst employed. Many of these are issues generic to any age: feeling well enough to job-seek; eliminating some career choices as incompatible with IBD; and fears about how and whether to disclose the IBD during the recruitment process.

Once employed, participants found mutual embarrassment when discussing the condition with employers and colleagues. Some feared the repercussions: the illness might be perceived as laziness, being disciplined or even sacked, not working near a toilet, the need to over-perform when well to offset fears of how IBD absence may be viewed, and not taking time off for things such as sprain ankle or colds to save up sick leave for the IBD.

Some had suggested home working and flexible working arrangements to their employer in order to cope better. This worked well for those who were often ill in one part of the day – typically the morning – and fine the rest of the day. This avoided the need to take a whole day off. Participants valued jobs in which they were in control of how and when they could do their various tasks.

Some participants felt trapped in their current job because of fears that another employer might not be as sympathetic.

In summary, participants prioritised their needs as:

- Understanding employers ***
- How much to tell colleagues **
- Understanding of an invisible illness **
- Disclosure of diagnosis *
- Will I get the same level of support with a new employer *
- Anxiety that the illness is perceived as laziness *
- Absence *
- Flexible working hours and venues *

These generic issues become specific to this age range because of the newness of the employment experience. A first job involves many 'firsts':

- proving yourself in an interview,
- feeling your way into disclosing a potentially-job threatening condition,
- coping with managers and colleagues, and
- developing a professional approach to achieving tasks and deadlines.

All these require maturity, self-confidence and interpersonal skills; and yet these often only come through specific training and through acquiring enough life experiences.

This area is important because:

Work is what normal grown-up adults do. Being in work is an important signal of socialisation and of one's ability to manage by one's self. It provides routes to self- and professional development, to recognition and respect from peers, to furthering ambition and of course to financial independence.

Fears that people in this age range have about employment may be more illusory than actual. We heard several participants who phrased their concerns as 'I'm anxious that my manager/colleagues/friends may be thinking...', or for example expressing fear that frequent absence is being badly perceived, without having checked the other person's point of view.

More fundamentally, however, the fears may well be based on real situations. Participants suspected discrimination when unsuccessful for a post. Others suffered the unfortunate consequences of honesty, the peculiar loneliness that unhappiness at work can create, stress aggravated by non-sympathetic employer, and the difficulty of 'managing' unsupportive colleagues and managers.

What people wanted:

- What questions to ask when applying for a job
- What support is available for disabled jobseekers
- What rights do I have – union support
- Programmes of information for larger companies; NACC naming the IBD-friendly ones
- Information at different levels: technical/medical/legal, to give to line-managers; day-to-day/practical, to give to colleagues
- Information about IBD to be not all framed in terms of the worst case scenario
- How to explain the impact of stress
- Advice on disclosure
- Advice on the Disability Discrimination Act and its applicability to IBD

Education

What people told us:

Our themed session on education produced three main areas of concern: communication with the institution; impact on academic work; and impact on home circumstances.

Communication with the institution involved getting assurance or active support – and in some cases, a basic acknowledgment of the condition and its impact. Participants had quite negative experiences, from the classic 'you look well you can't be ill' to the institution asserting it was unable to make allowances or provide specific support. Some students were told that they would be better off coming back when they were

better – a more-than-insensitive suggestion given the cyclical nature of CD or UC.

Participants were clear about the impact of their disease on academic work, particularly where attendance-based assessment is required. Participants had sought help in extending deadlines, and catching up on missed notes. One participant said she had to balance sedation against clarity of thought. There were several discussions about exams, and the benefits of being able to sit near the door with permission to leave as often as needed.

Participants who had successfully obtained Disabled Students Allowance were questioned closely about the process of applying and what benefits they could ask for.

"My uni really helped me push my assessment through and gave me loads of support. The assessment was fine, took about an hour and I just had a chat with the assessor who made things sound as bad as possible to benefit me most. I received payment for my laptop, a keyboard, mouse, laptop stand, printer, scanner, £100 printing and copying allowance and a £158 internet allowance."

"My DSA also supplied me with a laptop etc, but they also gave me a travel allowance of £100 to get a taxi if I feel unwell and need to get home quickly because it's about twice as quick as any of the bus routes."

Participants also discussed the impact on home circumstances – the stress for everyone involved, particularly around exams; coping with tiredness; and swinging between ignoring and accepting. For some, their disease influenced their choice of university ("*somewhere far enough but not too far*" [*Chesterfield to Manchester*]), for others further education was a valuable way of escaping from the parental home. As one participant said at the end of the discussion,

"We don't know how much of this ["I'm going to this University"] was simply about being adamant to your parents."

Participants prioritised the following needs:

- Coping with medication and treatments***
- Coping with symptoms***
- Attitude of staff**
- Relationships with friends and colleagues**
- Getting information*
- Disclosure*
- Managing my own emotional responses
- Issues around exams
- Catching up time

This area is important because:

Clearly, institutions need to balance educational standards and pupils' rights, and it is not surprising that standards are sometimes unreasonably relied on for not making adjustments. This should change as disability rights in the field of education become more established. IBD patients

have their place in this process by knowing and asking for what they are entitled to.

That said, there is no excuse for being told to drop out and restart your course when better. NACC's national profile in raising awareness thus is still of critical importance.

NACC has made progress in providing information on the Disability Discrimination Act and on advice to schools and higher education establishments, and there is of course the NACC information line. What is interesting is that our participants by and large didn't mention these NACC resources. They also requested information to be made available on topics for which an information sheet already exists.

For both this area of evidence and others, this suggests that participants

- might not be aware of what NACC offers (either they haven't looked on the website, or not found them easily enough and gone elsewhere);
- or, that they assume NACC will not have produced anything that they would find useful;
- or, that they don't automatically think of NACC as a place to go for this kind of information.

At the very least, then, NACC needs to be active in re-promoting its resources to this age group.

The web forum proved to be a useful means for participants to ask about DSA and to get responses from those who had been successful. This shows the value of peer-led resources such as the forum in answering specific queries without the need to take up NACC staff time.

People wanted:

- More communication with young sufferers
- How do I get help with job application and searching
- Help at uni where to get assistance
- Am I 'disabled' under the Disability Discrimination Act? If so, what does it mean?
- Knowing where to find out what you are entitled to
- Extra allowance for exams and coursework

Recommendations

Introduction

The big picture

It is worth highlighting some cultural contexts for NACC to acknowledge in reaching out to this age range.

- The spirit of the age is to get information but not to join. In other words, people want to know what is going on but resist signing-up or accepting a label in order to be kept in the loop.
- The trend is towards choices and "designing my own 'life package': what I interact with, how I find what I need, and who supports me". One participant said, "*What I need is access to what I might need*" – in other words, you [NACC] provide it and I'll decide if I want it.
- People seek support and affirmation from a number of sources, and loyalty is fickle. No single organisation, even one as comprehensive as NACC, can expect to be the sole or even a long-term resource for people in this age range with UC or CD.

Implications for designing NACC services

In the face of competing sources of information and support, NACC services have to appear interesting and easily accessible to catch people's attention. NACC must demonstrate it clearly understands and respects the issues for this age range and what is 'normal' for them.

NACC's dilemma is that one-third of its annual income comes from subscriptions, and yet amongst this age range an annual membership subscription doesn't represent the best way of encouraging loyalty. In accepting this, however, and in making itself an attractive option, NACC can hope to encourage people to include NACC in their "lifestyle package" - as members or as occasional users.

Not everyone in this age group is or behaves like a teenager! But those in most need of support (newness of diagnosis, or lack of life skills) are likely to be at the younger end of the age-range. These are the people NACC needs to make most sure of reaching.

Having seen first hand young people grappling with their life circumstances, we are convinced that NACC's most effective long-term contribution is enabling members to manage their own condition - in other words, NACC prioritising its facilitative and information-giving role ahead of offering direct support. The participant who said "What I need is access to what I might need", demonstrates a self-aware and self-motivated approach, which underpins NACC's role in enabling people to act as expert patients in all aspects of life affected by IBD.

As indicated in the Summary, this project was intended to produce a set of responses and ideas which NACC can use to devise specific services, activities or publications. These recommendations are therefore indicative of *an overall approach* for NACC.

Accordingly, Trustees may prefer to interpret the recommendations as **Areas for Action** rather than as a prescriptive list. NACC may also choose to focus initial efforts on a few areas, such as

- Promoting Young Adult Groups / Networks – see page 32
- Nurturing and developing the on-line IBD and DME community, by importing the existing discussion board and trialling the comparatively rare use (at least on other patient websites) of audio stories and podcasts of individual experiences – see page 33-4
- Trialling contact with members as they reach their 16th birthday – see page 30

Membership

NACC's future is to be found in people aged 16-29 with colitis or CD. If NACC fails to attract them, the risk is that they will learn to manage without NACC. They will also not understand or appreciate NACC's 'invisible' work on their behalf – lobbying, awareness raising and research projects.

Recommendations:

NACC needs to sell membership to this age range. We suggest two approaches: using the 16th birthday where a relative joins on their behalf, and providing a package of appropriate membership benefits which can be promoted generally to this age range.

Under 16:

Using the date of birth currently recorded on the membership application form, NACC should initiate contact with the young person as they approach their 16th birthday.

The intention will be to encourage them to take up membership in their own right, by offering reduced or complementary membership for a year, and spelling out the benefits of joining the NACC 16-29 community, and perhaps offering other benefits such as reduced conference fees. This process also has the benefit of giving them a small step towards taking ownership of their condition.

The offer of membership could be accepted by phone, entering a password via the members' area of the website, or by e-mail or letter.

NACC should retain the beneficiary system whereby membership can be purchased even for those over 16.

Membership package

Unhappily, the Can't Wait card and "We lobby on your behalf" don't provide attractive enough reasons to join NACC.

The alternative is the message "You can get from NACC what you need - and if you can't find it here then we will provide it or be the ones who help you find it." NACC will be demonstrating that it is fast moving, responsive and approachable. It reassures newbies that they are not alone. It will offer support for this age range not with the feel of a coffee morning or comforting support group⁵, but rather saying up-front "Welcome to our community. Yes these may be difficult times but you know what we could have some fun and help each other along the way."

Specifically:

- Literature and website wording that reflects the approach in the above paragraph
- Members Only section of the website - including a 16-29 section
- Access to the NACC 16-29 community (meeting in person and on-line – see p31 below)
- Access to peer buddying, mentors or befrienders
- Access to IBD-related workshops and study days for 16-29 years olds (as for Arthritis Care 'newly diagnosed' participants, and the EPP Children and Young People self-management programmes. Both are peer-facilitated, either by age and or condition, and address psychosocial issues, life skills and coping techniques. The EPP programme is cross-illness, finding that many conditions provide substantially the same day-to-day problems – socialising, employment etc).

Facilitating communication and support

Several linked themes stood out from the focus groups: experiencing times of poor body-image and self-esteem (due as much to treatment as to the condition itself), gaining and losing self-confidence, trying to find a sense of identity, and not having enough life skills. Everyone with a chronic condition needs to absorb that reality into their everyday consciousness. The trials and discoveries of being 16-29 add a further dimension. We feel that NACC can play a vital role in helping people with their skills, knowledge and values, and accepting that person as themselves.

A by-product of the ibdandme project is that via the web forum a self-sustaining, self-managing active community has been created. In

⁵ These support mechanisms are what older members particularly value, in contrast to one focus group participant who said "We want to talk about everything *except* our IBD." The EPP Young People and Children also found that the 12-18 age range also wanted social activities not related to the disease.

addition, there are those who have not joined the forum but who have registered their interest in the project via the NACC website.

This community has the potential to be developed in various ways:

- To provide information and support to its own members
- To be led towards national and local NACC membership, activities and fundraising
- To provide ideas and feedback on prospective NACC services
- To help shape the NACC of the future via policy input and trusteeship
- To provide an additional route for its members into the policy-making structures of NACC

The key means which have emerged for NACC to promote self-management are:

- Building and supporting this 16-29 NACC community
- Providing information on living day-to-day with inflammatory bowel disease, in addition to information on medical issues, treatments, facts about the disease etc.

Building, supporting and using the NACC 16-29 community

Communities can meet in two ways: in person, and on-line.

Meeting in person:

"I've realised from today that I'm not alone, that there are other people like me"

There were a significant number of participants who indicated that they had never previously met anyone else their age with colitis or Crohn's Disease. Not everyone is able or willing to meet together in a group, but its obvious benefits are worth the effort of overcoming geographical difficulties.

Local Young Adult groups/networks

- Continuing to support local Young Adult groups across the UK, either as part of an existing adult Group or as a separate network. To this end, the ibdandme community offers scope for recruiting both coordinators and local participants.
- In supporting young adult group/network coordinators, NACC could offer: an e-forum for young adult coordinators; their own regular section in the magazine; podcasts by existing coordinators (e.g. "this is how I set up my own local young adult group"); and a resource pack and FAQs for potential coordinators. The existing Young Adult Framework could, we submit, be re-written by existing young adult coordinators to ensure its language and advice are directly relevant to the people NACC is trying to recruit.
- Enabling young adult coordinators to compile and manage e-mail lists for local group participants

- We know that NACC takes a positive and pragmatic approach to its local groups – they undergo stages of life, and will flower, wither and re-sprout according to local need and personnel. The same is true for groups involving this age range, whether on-line or in person – except that the life-stages are likely to be much shorter!
- Adding to the Local Group contact details on the website: e-mail contacts (where they exist) for Young Adult coordinators, to help the 16-29 age range communicate more easily with their local group
- On the website, identifying young adult groups as a separate category of local groups, as well as including them in the regional listings

Other recommendations for meeting in person:

- National young people 'get together' days along the lines of the ibdandme discussion groups but with speakers, workshops, ideas sharing and social time. Existing models include the EFCCA's European Youth Group Conference, and Kati Maskell's London Young Adults session on 14 October 2006.
- Providing a 16-29 equivalent of NACC-in-contact, staffed by 16-29 old volunteers. A group of young people with IBD could quickly generate a suitable-sounding name for the service. As an interim measure, Contacts in this age range could be trained up within the existing service and be identified as available if a 16-29 year old needs support.
- The existing NACC-in-contact could be promoted in part by giving examples of the sorts of questions young people ask (perhaps via a magazine article or on the web), to show that NACC is already responsive to this age range's needs
- Peer buddying, mentoring or befriending. NACC's experience of the Counselling Service shows that such schemes need a structure and support mechanisms; so they are not suggested lightly. Based on evidence from participants, they have potential to offer a quite transformational impact on the recipients.
- Supporting IBD nurses and local clinics to offer hospital-based meeting opportunities
- NACC may feel it needs a Young Person's Development Officer in order support activities for this age range and to promote membership take-up
- Several participants asked about the availability of counselling, although we are conscious of the cost implications of NACC facilitating such a service and its experience of having provided a similar service in the past.

Meeting on-line

As indicated, there is a ready-made on-line community, which NACC can adopt and nurture. NACC should make available a variety of ways for the community to meet on-line. The vision is of a community communicating with itself, informing and supporting its members, giving feedback to NACC about what they want experience and what they want, and providing a channel for NACC to communicate with this age range.

The spirit of the internet is: engagement, community, interactivity, and communication. This is also what this age range have been saying to us so

clearly. A successful NACC site doesn't have to reach huge numbers; success comes from being big enough, reaching enough of the right people. "Top-down" communication is no longer enough; and anyway, it's wrong to assume that the bottom is the bottom any more – via the web, anyone can be a publisher, broadcaster, advocate, opinion-former.

Recommendations:

- A young people's area on the website, drawing on examples such as www.crohns4youngadults.org.uk and www.cicra.org
- A web forum, along the lines of the current www.ibdandme.nacc.org.uk with the opportunity for NACC staff and trustees to join in posting comments as appropriate ⁶
- Advertised regular chat-rooms, say one or two evenings a month. They could be either general discussions, or with a guest member such as 'expert of the month', or local young adult group coordinator on running their local group, or IBD nurse, or a NACC member with a specific experience for sharing and discussing. See www.crohnszone.co.uk for an example of general discussions taking place every Thursdays and Sunday evenings, 8.30pm.
- Audio or video downloads (podcasts) of selected 16-29's experiences, ideally in response to response to issues raised by community members
- A "Just been diagnosed" quick link on the NACC site, (as for www.ccfc.ca but with simpler and shorter text). This link could provide essentially the same information in a Bounty Pack available for members newly-diagnosed
- A message posting service to NACC along the lines of the "Readers' medical queries" in the NACC News, ideally responded to by an IBD nurse or gastro or the Information Service. See www.epilepsy.org.uk/youngpeople/index.html for an example ("Dear Danny...", "Dear Debbie...")
- Using the web area or instant messaging (example: "Sign up to be consulted!") to bring 16-29's voices into NACC decision making, thus promoting NACC's accountability and bringing in new ideas/insights. (Example for Colitis and Crohn's week: asking for responses to 'What messages should be promoted for young people, and how should NACC promote them?')
- Links to NACC staff for volunteering, or for joining project/ideas teams
- Link for "Want a mentor/buddy/pen pal?"
- IBD lends itself to blogging ⁷. NACC could host blogs, provide links to individual members' blogs. It could even commission specific blogs from members undergoing specific IBD-related experiences (diagnosis, ileostomy, surgery, new drug regime, "a week in the life with colitis")

⁶ Much has been learnt from the experience of running the ibdandme web forum. In particular, moderating postings can be time consuming, whether it is done as a filter before postings are uploaded, or after posting as for the ibdandme web forum.

⁷ Blogs are on-line daily diaries which anyone can read and add comments to. As a comparison, Sally Sargeant successfully employed diaries for her recent NACC-sponsored research into IBD and adolescence.

etc) as a way of informing and supporting those facing or undergoing similar experiences. See www.arthritiscare.org.uk/LivingwithArthritis/Joshsdiary for an example of a blog of someone facing an operation

- www.myspace.com enables people (primarily young) to hang out online. Members can build their own profile – pictures, text, music, interests... For this age range, it's a natural way of expressing oneself and of creating your own identity visible far beyond those closest to you. NACC could create its equivalent for people to 'locate' their identity on NACC's site.

As mentioned above, <http://www.crohns4youngadults.co.uk> is a relevant example of a healthy active site. It has a 'members stories' page, space for newbies to introduce themselves⁸, news stories, and information about CD. See also the 'Avatars' area to help people identify themselves; what images might NACC choose to offer?, or – more engagingly – find it is hosting when it enables members to add their own examples?

How other charities do it:

www.arthritiscare.org.uk, to see examples of: a blog from someone about to undergo an operation; a web forum for young people as well separate forums for 'all ages'; a helpline for under 26 year olds and their families; a section for young people's information (in Publications and Resources); a list of local groups which includes young people's groups.

www.diabetes.org.uk, to see examples of: a teenzone 'young people only' area on the website; links from the teenzone to both fundraising and 'join the campaigns network'; a magazine for teenagers.

www.epilepsy.org.uk, to see examples of: a separate teenage section within the website; simple short pages of information for young people; a podcast from a patient's relative; an on-line Q&A service to ask about any aspect of epilepsy.

www.childliverdisease.org, to see examples of: putting families in contact with each other via the web.

www.ibsnetwork.org.uk, to see an example of a befrienders scheme.

Providing information

There was a significant proportion that wanted help and advice on living long-term day-to-day with IBD – in other words, not information about the technical and medical aspects of the condition. People identified the value of hearing others' experiences as a way of getting support and in facing their own issues on a day-to-day basis.

Some of these topics already exist as NACC Information Sheets. Nevertheless, in giving the following lists we have prioritised from amongst the areas of doubt and anxiety which surfaced during the discussion groups, as they represent the areas where information specifically targeted at 16-29 year olds is likely to be most welcomed.

⁸ Participants created at least three similar strands on the ibdandme forum.

It is important to capture an appropriate, and accessible, style and layout for information sheets which are likely to be ready primarily by people in this age range.

“Living day-to-day” information sheets:

- Past experiences – in other words, what’s happened to earlier 16-29 year olds, and how has their experience progressed?
- Relationships, sex and you
- The social aspects of being at university
- Pain management
- Top tips for partners of people with IBD
- How to be a good enough IBD parent
- Help with the journey of acceptance: positive experiences

“Technical” information sheets

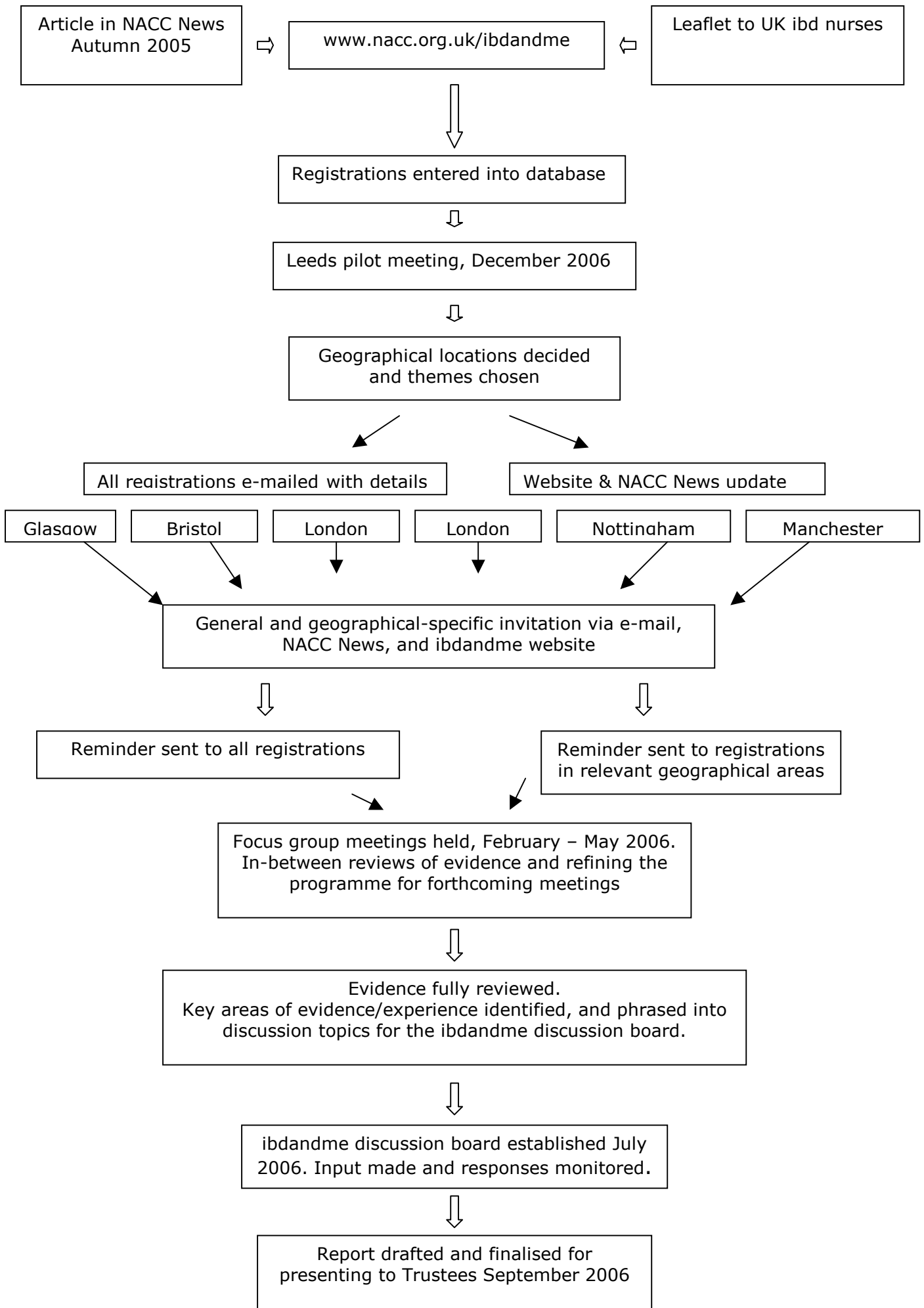
- Pregnancy and parenting (One participant directed us to the article at <http://pregnancytoday.com/reference/articles/bowels.htm>, which is cut and pasted on to the <http://www.crohns4youngadults.co.uk> discussion board)
- IBS and/or IBD
- Steroids – their use and effectiveness, and their side-effects and long-term consequences
- Disabled Students Allowance
- “NACC Best Practice” advice to the medical profession in caring for 16-29 year olds with inflammatory bowel disease
- Similarly, “NACC Best Practice” advice for education establishments and employers
- Employment law/rights, Disability Rights Commission, Disability Discrimination Act definition of disability
- Bowel management and urgency
- A ‘Just Been Diagnosed’ information sheet aimed at mid-teenagers
- Complementary therapies

Further research possibilities

The following emerged as areas of concern which may be suitable for future research projects

- Pregnancy, young people and IBD
- Men and women aged 16-29 and their emotional responses and coping mechanisms for diagnosis, acceptance and disease management.
- Long-term effects of medication.

Appendix 1: Methodology



Appendix 2: Information from NACC's membership database

Members aged 16-29:

Age	Female			Male		
	UC	CD	IBD	UC	CD	IBD
16	4	9	-	1	5	-
17	5	17	2	7	15	2
18	13	28	2	17	21	2
19	15	48	4	13	29	3
20	29	48	3	13	27	3
21	31	58	11	21	32	2
22	39	87	5	16	39	3
23	40	93	8	32	39	2
24	65	98	3	20	43	3
25	51	105	9	43	58	3
26	82	117	11	40	59	8
27	72	114	14	42	64	8
28	82	137	15	41	52	6
29	81	144	7	50	48	8
Subtotals	609	1,103	94	356	531	53
Overall total:	1,806			940		

Number of relatives joining for 'child' aged 16 – 29: **210**