Improving Standards of Care for Colitis and Crohn's Disease

NACC Patient Focus Groups

(held in December 2004 and January 2005)

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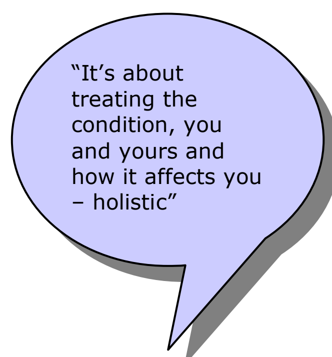
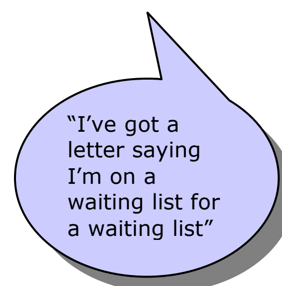




Background and introduction

NACC is engaged in the preparation of *Standards of Care for IBD*, as part of its involvement in the British Society of Gastroenterology's IBD Section Committee. *Standards of Care* focuses on all relevant health services, including primary and secondary care, and its drafting involves a partnership of medical and patients' organisations. NACC is keen to ensure that the document sets standards that patients can use locally in accessing and improving the services they need.

NACC sees IBD patients as critical voices within the drafting process. To that end, NACC ran two focus groups for IBD sufferers and carers. The groups were designed to enable participants to:

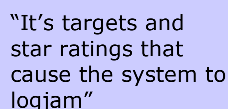
- Identify and reflect on their experience of health services for IBD;
- From that experience, identify which aspects of care are most important to them, and which most need to be improved and how.

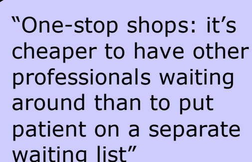
The groups took place in two cities, one in the North of England on 11 December 2004 and one in Scotland on 15 January 2005. In all, about 30 NACC members with a range of conditions and experiences took part.

One unforeseen outcome was that participants began comparing their own experience of treatment – sometimes within the same hospital or by the same consultant – with that of other members of the group. This shows that by meeting together, patients can share best practice and encourage each other to ask the system for the best it can offer. There are many opportunities for patients to do this – in groups such as these, in NACC local groups, and in Patient Panels and Forums and Expert Patient Forums.

This report draws out general themes and reflections arising from the group. With a view to articulating the aspirations of IBD patients, the report also presents a series of ideal journeys through the healthcare system. The raw data from both groups is written up word-for-word in Appendix 2. The quotations appearing throughout the report arose from the two groups.

Both groups were facilitated by John Gray of Framework, a small network which since 1985 has provided ethical consultancy, facilitation and training to not-for-profit organisations in the UK and abroad.

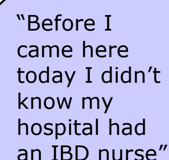




Taking forward the work of the focus groups

In receiving this report, NACC staff and trustees should consider and decide on

a) whether to invite further patient contribution, perhaps via a downloadable copy on the website, via an article in NACC News, or by testing with cherry-picked NACC members able to add their input
b) by reference both to the process and the outcomes, how to utilise the experience of these groups to inform NACC's Nursing awareness campaign and its involvement of young people



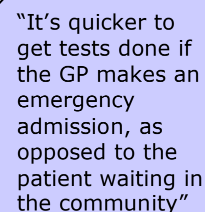
The outcomes from the groups should be cross-referenced with the current draft of Standards of Care. What is confirmed within the draft, what's new, and what needs emphasising further?

The report should be sent (without Appendix 2, the raw data from each group) to those who attended the groups or who expressed an interest in being informed.

Emerging themes and patient priorities

Arising from individual experience, the following are common examples of how the healthcare system more than met patients' expectations:

- ✔ Good involvement from GPs and IBD nurses
- ✔ Providing 'holistic' health care – reducing stress, involving the patient and their family, being willing to discuss complementary therapies, and cross-team collaboration and communication amongst professionals
- ✔ Providing emergency treatment
- ✔ Offering what patients particularly value, namely support and time



In comparison, the system is most likely to let people down when:

- ✗ GPs don't know about IBD
- ✗ Parts of the system don't communicate – the most frequent example was hospitals not keeping GPs informed
- ✗ There is lack of consistency in care, particularly when patients see a different professional at each appointment
- ✗ There are delays in the system, for investigative procedures and especially in the availability and timekeeping of outpatient appointments
- ✗ Professionals have poor understanding of the ramifications

of IBD, or don't treat the patient as a person

✗ Insufficient information is provided

In response to '*in relation to you and IBD, which part of the healthcare system most needs to be at its best for you?*', patients' priorities are:

- Greater awareness of IBD amongst GPs
- Better communication between GPs and consultants, and within the 'system' generally
- Better management of outpatient appointments, and greater staff continuity during routine management of IBD
- The quality of support (practical and emotional, and by giving information) that professionals offer

Both groups designed the patient's ideal journey through the healthcare system. Although not limited by current realities or budgetary restraints, the responses were nevertheless very revealing. Patients' ideals rest more on *attitudes of professionals, good organisation, good communication, and better awareness of IBD and its implications*, than on additional resources within the healthcare system. This suggests that the healthcare system does not need to invest more money in order measurably to improve its treatment of IBD patients.

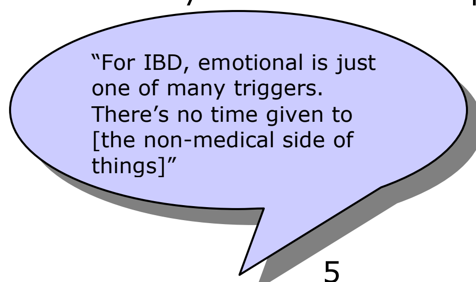
As a result, some priorities begin to emerge for NACC, local groups and patients with IBD.

There are key parts of the NHS which could be targeted to **improve standards of care**: awareness of IBD especially by GPs; encouraging – and even facilitating – greater communication between professionals; and streamlining outpatient systems (perhaps by trialling 'one-stop shops' for IBD, as one participant suggested). Not all outpatient services need to be provided by the hospital. The possibility of low- or no-cost improvements should be highlighted.

Professionals should be encouraged to give patients **greater respect and involvement** and respond to their condition in the wider context of their lives – 'holistic' was used several times in both groups.

Patients can use their individual expertise of their illness to **become active in the treatment they receive**: asking for time, for information, for support; and seeing themselves as active participants in deciding the treatment they receive. Some are already working towards this, for example by making day-to-day decisions about how much of their medication they take.

In other words, patients **should not be shy** in responding to Alan Milburn's promise that they should take their place 'at the heart of the NHS'.



The ideal journey through the healthcare system

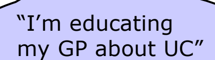
"My diagnosis and investigation:

I am able to obtain a prompt GP appointment, and I have enough time within the appointment to describe my symptoms. My GP listens well and likewise has time to carry out initial investigations. She has enough awareness of IBD to consider it a possibility from the outset rather than as a last resort, and together we discuss conclusions and options, and reach a decision together.

"The GP explains why she is referring me – but not giving so much information that I overload, as I am already feeling bewildered and confused about the implications of diagnosis. Nevertheless, the GP opens up the computer and arranges a hospital outpatient appointment there and then, as soon as my symptoms warrant it. I am referred to the appropriate specialist or consultant.

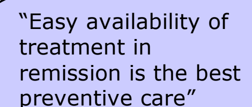
"I see the specialist at the time of the outpatient appointment. We have enough time for her to explain all the investigative tests, and I am given full information to take away. Afterwards, I have time to meet with the IBD nurse who offers emotional support and answers the questions I forgot to ask the consultant. She gives me the number to contact her on.

"I get the test results within a week, and within a week of the results have a further appointment with the consultant who gives full explanations and consequences of the diagnoses. Related conditions are explored, and I am introduced to the professional team who will be caring for me. I am also told about NACC."



"When I am admitted as an emergency to the hospital,

My GP recognises the need, informs the consultant and arranges my admission. I am met at the hospital by an IBD specialist, and swiftly admitted to a medical ward (not A&E). Good communication ensures that general nursing and specialist staff are aware of my condition and the symptoms I am experiencing."



"When I undergo non-emergency surgery,

All attempts by the consultant and myself to manage the illness without surgery have failed. Surgery is chosen as a last resort, and I am given full information, and jointly make a decision about surgery with the consultant. My

family and I are able to make good preparations, and the date of the surgery is chosen to take account of my circumstances.

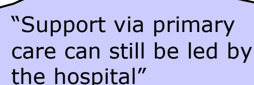
"Before the surgery, I meet with specialist nurses, and with other patients who have undergone similar medical procedures. I am introduced to the surgeon before the operation, and meet her again afterwards. Local voluntary agencies and medical staff help me prepare for the social, employment, educational and psychosocial implications of the surgery. There is on-going communication between gastroenterology staff and the surgeons."

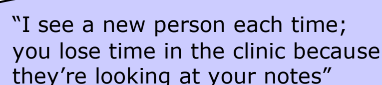
"For my post-operative care, and in transition from in-patient to out-patient,

I am prepared with information about what I can expect after surgery. I have a bed close to the ward toilet, and have continued contact with the gastroenterology team.

"As the prospect of discharge approaches, I am involved in discussion with ward and gastroenterology staff and my GP and other community-based staff. We negotiate a discharge date together. I am given a care package which is clear and comprehensive, and informed by ward visits from the dietician, physio and other relevant professionals. The care package includes a GP appointment (at home or at the surgery) and my next outpatient appointment.

"I go home with a reasonable supply of medication, knowledge of how to contact the hospital if needed, and knowing that there is a swift and easy re-admission process if necessary."





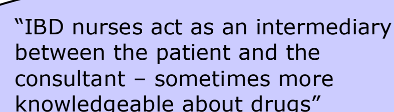
"In the routine management of my IBD, including outpatient appointments,

There is clear agreement as to who is responsible for my monitoring and treatment – my GP, specialist nurse or consultant. I am made aware of services available at the hospital, in the community and in the voluntary sector; and I have the opportunity for peer support.

"I have a review with my consultant of my condition – annually, or less frequently if my symptoms warrant it. The review includes any side-effects or long-term implications of my medication, appraises my emotional as well as my physical well-being, explores new treatments, and answers any anxieties I may have. The consultant takes a long-term view, in other words seeing my treatment beyond simply the date of my next appointment.

"In the meantime I have easy access to a specialist nurse or other relevant professional. I have confidence that the system will be able to respond as soon as I need anything more than routine management of my condition.

"When I have an outpatient appointment with my consultant or specialist nurse, I am seen at the time on the appointment card, and by a familiar face who knows my case. Other professionals are available for me to see following on from the appointment as needed, such as the specialist nurse, dietician or pharmacist. If I am feeling well, I am able to postpone the appointment rather than enduring the following dialogue: "Are you well?" "Yes." "See you in 12 months' time, then." My hospital uses internet consultant appointments for when I am in remission, and is introducing patient-held records for people with IBD."



"When I am required to make major choices,

The system first acknowledges that it is *my* choice. I am given enough information about the alternatives, and enough time to decide. Where appropriate, I am able to consult my family or involve them in discussions with professionals. I find out about the risks and benefits, by talking to professionals and by using lists of resources provided by NACC, websites, books and leaflets. I have the chance to reverse my decision once it is made. Medical staff are supportive of my decision and the implications it has for me."

"In managing my associated medical conditions,

I have enough information about my disease to know which symptoms or concerns to raise with my consultant. My consultant has enough time with me for her to notice any associated medical conditions.

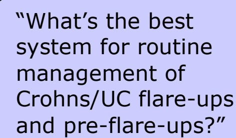
"Once such conditions are identified, their management requires effective communication between professionals, and the good use of multi-disciplinary teams. A clear decision is made as to which is the primary condition, and thus whether the IBD team has overall management of my other conditions.

"Coordination focuses on the impact of all my conditions and their treatment, including the complementarity of all my drugs and their side-effects. I hold an outpatient drug card for my medications. I have a coherent strategy for my medication which is reviewed appropriately and via joint appointments with relevant professionals. I am fast-tracked between the various hospital departments, to prevent delays in treating one condition having a negative impact on other symptoms."

"Within my non-medical support and care,

My NACC local group is an invaluable source of support for me and my family. I have the opportunity to meet other patients, and talk to others who share similar problems. Sometimes my NACC group runs family/carer-only sessions – no patients allowed! My emotional well-being is improved by being an active participant in the local group.

"I know where and how to access the information and support I need. What is available is accessible to me. Information is also available to people who *don't* have IBD – parents, families, employers, schools and colleges, statutory agencies and businesses. Counselling services, social services, the Benefits Agency, my pharmacy – all know about IBD and are able to respond appropriately. The greater awareness of IBD throughout the community makes my condition ever more easier to manage."



"Everyone's on review; you get told to come back in three to four months, but it takes a year to get an appointment"

"Specialist nurse couldn't give me more information than consultant – and having seen the nurse regularly, it was more difficult to get back to seeing the consultant"

Appendix 1: Programme

Programme:

11.00
Welcomes and introductions to the overall process and the day itself

11.20
'The best and the worst': what sticks in your mind, when did the system fail you, when did it exceed your expectations? (small groups, feedback and large group discussion). Prioritisation exercise: '*In relation to you and IBD, which part of the healthcare system most needs to be at its best for you?*'

12.45
Lunch

1.30
Light and lively

1.40
The patient's ideal journey' through parts of the healthcare system. What needs to be offered, said, and provided? Small groups and feedback.

Parts of the system:
- Diagnosis and investigation
- Emergency admission
- Non-emergency surgery
- Post-operative care
- Transition from inpatient to outpatient
- Making major choices
- Outpatient appointments with consultant or specialist nurse
- Routine management of the IBD
- Management of associated medical conditions
- Non-medical support/care

3.00
Thanks and closure

Appendix 2: The raw data

The following material has been anonymised. The data in black is from the English Group, the data in purple is from the Scottish Group.

The best was when…

In emergency, treatment prompt and reassuring
Clinical nurse essential as point of contact and screening mechanism
Going private
Hospital appointments system worked well until 2002; system accessible until 2002
Feeling 'safe' in the hospital system
Excellent treatment in hospital (first admission)
Good teamwork and feedback on my progress; swift endoscopy
Consultant's secretary is good but we have to be proactive
Specialist IBD & stoma nurse is good
Good bone marrow density testing
Good response in emergency for outpatient appointment
Listened to and believed by specialist nurse; has time, contact point to shortcut system, information, benefit of communication between disciplines
Consistent doctor relationship
Inclusion of family re information, process, awareness of impact
Benefits system from nurse
Intro to NACC
Information of and from drug companies
Given written information
Specialist nurse: relationship, knowing over time about how much an individual can cope with (or not)
Access to team
Instilling confidence in own management
Info to decrease stress
Drop-in clinic/time
GP in the loop
Team collaboration – several depts, pharmacist
Complementary therapy if it works for you
More cautious use of certain drugs

Support from physician when first diagnosed
Reassurance when first diagnosed
Ability to get colonoscopy
Support from GP
More time needed for discussion with patients
Access to specialist nurse – treatment, drugs
Stoma nurses very supportive

Weekly meetings of lead consultants and specialist nurses – leads to good communication
Health professionals worked as part of a team, especially when treatment required for other illnesses/conditions
GP's care and ability to deal quickly with problems
Nursing care (inpatient)
Direct contact with IBD nurse
Speed of diagnoses – home to hospital
Ongoing monitoring
Good if you know how the service works
Getting a second opinion
Seeing same doctor
One-stop shop – better service
Access to best treatment

The worst was when…

GP unaware with respect to IBD symptoms
Lack of follow-up in clinic after diagnosis
Lack of continuity in terms of the doctor one sees and associated unfamiliarity with notes
Clinic delays – despite consultant saying 'I want to see you again in 3 months'; waiting a year to ask a question
Telling the GP what the consultant prescribed me
Delays in ancillary clinics e.g. bone scans
Government targets distorting appointments system? It has serious clinical consequences ie relapses exacerbated by insufficient care
Mis-labelled with IBS and given Prozac
Emergency admission before diagnoses – insufficient knowledge by GP
8-9 week waiting list for endoscopy (outpatient, not inpatient)
diagnosed with proctitis and discharged with no follow-up (yet is a common precursor of UC)
hospital did not connect up 2 episodes of care
Outpatient follow-up from admission – 4 weeks not 2, saw a different doctor, and it wasn't the consultant
Getting outpatient appointments
Patronised
Doctors do not acknowledge mental state and impacts on illness
No specialist nurse
Link UC and smoking not explained
Doctors don't ask the right questions
Poor diagnosis and community/primary care
Struggling at work
Loss of understanding
Implication of long-term illness
Seeing different person each visit
9 mins out of 10 min appointment spent on medication and history
loss of seamless journey
'Here's the diagnosis, here's a phone no., goodbye'
lack of benefits advice

NACC ignored by clinics
No information on side-effects of drugs and types of drugs
Sent away with just a 6 month appointment
Lack of information on accessing system quickly
Personal choice re medication/operation
Dietician
Lack of detailed information e.g. 'eat a balanced diet'
Stress – overload of information
Time delay in informing GP
Time lapse between test procedure and knowing results
Flagging up allergies etc
"I am individual not a patient statistic"; "doctor knows best but I'm the expert patient"

When communication breaks down
When GP's don't understand or don't have time
When GP's don't treat you as a person, just a disease
When services aren't quickly accessible
When additional information is missing ie referral to NACC, referral to dietician etc
Lack of consistency – information, staff
Poor understanding of symptoms by some nursing staff
Allocated time for appointments [vs time actually seen]
[Limited] availability of treatment eg colonoscopy
[Poor] quality of information/diagnosis – hospital and GP
Monitoring of patients in remission
Awareness/effects/options re mediation
Lack of information
Lack of continuity (doctors
Lack of emotional support
No info regarding NACC
Side-effects of drugs (little info given)
Discussion alternative therapy
Time to talk
'Get in touch if you have any problems' – but how?
Ongoing monitoring
Incorrect information
Choice of medication
Cost of drugs
Not seeing same doctor
Different opinions
Not seeing consultant quickly
No beds available
Poor availability of nurses
Split-site hospital
Waiting time for scans
Bone scan criteria not published
Pain relief – no direction

Prioritisation: *In relation to you and IBD, which part of the healthcare system most needs to be at its best for you*?

From the English Group, four main areas emerged:

1. The NHS!; The whole system (**connectivity**); The system ie after-care, follow-up, on-going support and connection of bits; communication within the whole system

2. **Diagnosis** by GP; Diagnosis and management; GP knowledge of IBD

3. Transition from GP to hospital; **communication** between hospital and GP; Links between individual, GP and hospital – easier and quicker communication between all three

4. **Out-patient appointments system**; Value and content of appointment time with consultant (ie not registrar); Seeing same doctor/nurse for each appointment; Aftercare as an outpatient – continuity and availability; Continuity in treatment

And from the Scottish Group:

1. Would like them to give you more new **information**; Clearer information and discussion of options; Availability and information; Proper information about side-effects of drugs; More up-to-date information

2. **Ease of contact** with consultant; Speedy access to consultant; Rapid response to problems when an outpatient; Appointment to surgeon when required; Contact: easy accessibility to medical services; Better outpatient services/access; More access to dieticians, surgeons etc; Access to outpatient clinic ; Quality of diagnoses and continued monitoring

3. **The need for communication in the health system:** Regular communication between health professionals; Multi-disciplinary team communicating and working together

4. Ongoing **support**; Quality of support

The patient's ideal journey through…

Diagnosis and investigation

- Fast response for GP appointment
- Longer than 5 min appointment. GP needs to listen and carry out initial investigations quickly to aid differential investigations
- GP gives clear explanation of why referral is made (not overload of information which may cause panic)
- Open computer and arrange OP appointment there and then with choice of consultant – patient asks GP: 'if you had this problem who would you like to see?'
- Outpatient appointment within 7 days
- At outpatient appointment: seen at the appointment time, by consultant, for however long it takes; explanation of procedures (not just being given a leaflet); include family if requested
- Ok to spend longer time with nurse for fuller explanation and leave with contact numbers
- Investigations complete within the week, results within the week, follow-up appointment within one week of results
- Consultant sends copy correspondence to patient as well as GP

And,

- Quick access to GP appointments
- Time to discuss your condition - conclusions reached, options
- Agreement reached and action taken
- If IBD suspected, referral to consultant. Appointment arranged there and then, for as soon as condition once. Think of Crohn's or Colitis first, rather than after everything else has been investigated
- Giving you proper information about investigation
- Within a week, with test results: Full explanation and consequences. NACC info. Drugs. Surgery. Introduction to professional team. Explanation of related conditions
- Regular monitoring of condition, irrespective of current state of health

Emergency admission

- GP recognises poor condition
- GP informs consultant
- Consultant gets you in
- Admission to medical ward, not A&E

And,

- GP should decide it is an emergency (not consultant)

- Recognition that emergency admission is disruptive – sort out home and family needs
- Met at hospital by IBD specialist
- Good communication between nurses and medical staff, to facilitate treatment and help to speed process
- Swift admission to ward
- Depending on severity, making nurses in A+E and ward aware of patient is suffering – lines of communication, understanding

Non-emergency surgery

- Full information, pro's and con's, choices
- A mutual decision between patient and doctor
- Doctor aware of patient's stress (if surgery is being considered, patient unlikely to be at their best)
- Understanding and negotiation of patient's needs
- Surgery seen as a last option, not a default option
- Promoting confidence
- Post-operative information

And,

- Try to avoid it by illness management
- Information gathering leading to informed choice
- Good preparation for self and significant others
- Meet stoma nurse before admission if appropriate
- Meeting others with e.g. ileostomy
- Voluntary sector partnership with statutory agencies
- Implications for 'life at large' – education, employment, social, psychosocial
- Ongoing good communication between gastroenterology and surgeons

Post-operative care

- Information on what patient can expect post-surgery
- Discussion forums on NACC website
- Bed close to toilet
- Chance to talk to surgeon before and after op (studies show this speeds up recovery time)
- Negotiated discharge date
- Easy re-admission
- Continued contact with gastro team
- Reliable support
- Routine home visit from GP after discharge

And,

- Coordinated
- Fully-informed

- Clear diagnosis
- Regular appointments
- Continued support

Outpatient appointments with consultant or specialist nurse

- Appointments when required, not altered, seen by a familiar face who at least knows your case
- Opportunity to cancel and reschedule appointments if all is well
- Specialist contact e.g. IBD nurse, dietician, for emergency or reassurance

And,

- Clearly defined role for specialist nurse, known to patient
- Internet consultancy with doctor
- More doctors (registrar)
- See same/named doctor
- Better appointment system to meet patients' needs ie appointment takes place as prescribed

Routine management of IBD

- Educate doctors – hold patients' experience sessions within training
- Accessible fact sheets
- Choice of opportunity for peer support – local groups, publications, NACC news etc
- GP should have sufficient info – and patient is included in the loop
- Appointment by request
- Minimum annual contact between patient and consultant – builds confidence
- Open access to specialist nurse
- Refer to NACC/support group

And,

- Agreement on who mages your monitoring and treatment – GP, specialist nurse or consultant?
- Meeting on an agreed regular basis with your specified health professional
- Periodic review of medication prescribed and/or treatment
- Make patients aware of services available (GI nurse, who to contact in emergency etc)
- Appraisal of emotional well-being, even if medical condition is still the same
- Ability to be able to speak to your chosen health professional whenever you want
- Uninterrupted channels of communication between consultant – GP – patient
- Free prescriptions

- Patient-held records

And,

- Access and appointment to see your named consultant at least once a year
- Review of medication at time of consultation: info on drugs, side-effects (short and long term), new treatments, alternative treatments, checking any other anxieties you may have – treating *holistically*
- Regular contact between GP/hospital (GPs in Scotland will soon be more involved/active/doing what hospital has done to date
- Access to nurse specialist either by phone or 'regular' appointments
- No time constrains at clinic appointments
- Having consultants who will look at the time long terms view (what may happen, longer-term consequences of treatments, best guess at future), and who have the ability to speak to you as a person
- Having quick access to services as and when required – doing this via only one point of contact

Management of associated medical conditions

- Need to be told about main effects of main condition
- Need to be told about subsidiary effects of main condition
- Need to be told about side-effects of medication
- Need to be given a coherent strategy of medication – ie long-term diagnosis, long-term monitoring
- All of this preferably at one sitting
- All of this subject to overall review (taking into account other possible conditions)

And,

- Multi-disciplinary teams, associate consultants and professionals
- Drug management
- Fast-track around medical disciplines
- Outpatient drug card (similar to pharmacist oversight of inpatients)
- System for drugs
- Monitoring patient card

And,

- Having enough time with the consultant so that s/he can notice associated conditions
- Consultant to notice & make the links
- Patient has sufficient info to be able to raise possibilities or concerns about associated conditions
- Communication to be whole-team discussions, joint appointments with relevant specialists and patient
- Communication from patient about which is the primary condition
- Communication between consultant and other relevant professionals

- Clear choice about whether the IBD team has overall management of other conditions
- Option of appointments for all conditions at same visit

Non-medical support and care

- NACC – source of advice and info
- Contact for new patients
- Counselling for patients and carers
- Medications utilise the support of the hospital and local pharmacist
- Take opportunities to talk to others who share your problems
- Alternative therapies
- Social workers, benefits agency

And,

- Availability of info for others (not sufferer) about IBD, tailored for particular user-groups ie parents, families, employers, schools and colleges
- Mechanism in place to direct people where to obtain information
- Awareness and access to support services eg social services, counselling, NACC
- Support from local group members and NACC-in-Contact service
- Greater awareness in the community through higher profile of IBD

And,

- Finding out where to access what's available and finding out what actually is available
- Does what you've found out meet your needs and is it accessible to you?
- Having information available in clinics for easy access – ie books, internet, booklets, NACC address etc
- Having family access to NACC resources/meetings – providing family support

Transition from inpatient to outpatient

- Clear care package (medications, outpatient appointments, GP informed)
- GP communicating with hospital about treatment if required
- Telephone contact at the hospital (IBD nurse, consultant's secretary)

And,

- Forward planning by staff, patient, pharmacy, community (GP, District Nurse)
- Staff to involve patient in deciding discharge date
- Ward visits from dietician, physio etc prior to discharge with clear written info where needed

- Knowing what to expect: regular clinic appointments (which whom, where, when), reasonable supply of medication, GP letter and appointment
- Hospital contact information – who/where, the telephone number, is it 24/7?
- Going home with written info for you and your family

Making major choices

- Being allowed to make a choice
- Getting information (and alternatives) to make the major choice
- Time to be 'allowed' to make the choice – as long as possible
- Can you choice be reversed – and when?
- Medical staff acceptance of your choice and supporting the choice you have made

And,

- To have the chance to make a choice
- Information about sources of info, eg websites, specialist nurses, NACC, books, leaflets etc
- Clear information about risks, benefits, outcomes, including opportunity to speak to specialists and other involved professionals
- Time and emotional support eg discussion with family, friends etc. and others to have opportunity to be present in consultations
- Sometimes the choice needs to be written down

In answer to specific questions from Richard, one group indicated:

1. That most of them would happy to receive two months' worth of medication for each prescription (rather than the standard one month)
2. That most of them independently decide how much they take of their own prescription, although their consultant usually knows that they are doing this
3. That they would prefer specialist nurses to have authority to prescribe medication [Richard – I think this was the response to your question, but please change if need be]

A 'timeline' showed that half the members of one group lived with a diagnosis of IBD for four years or more before they first heard about NACC.