

Adolescence into Adulthood in
Inflammatory Bowel Disease (IBD)
The Transition from Paediatric to Adult Care
Meeting at the Royal Society of Medicine,
London, UK

MEETING REPORT

16 June 2005



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Introduction to the report

Transition from paediatric to adult care has been increasingly recognized as an important aspect of the organization of healthcare services, and is particularly important in diseases such as Ulcerative Colitis and Crohn's Disease, which are very often diagnosed during childhood or adolescence. Therefore, in the autumn of 2003, The National Association for Colitis and Crohn's Disease (NACC) and Crohn's in Childhood Research Association (CICRA) – two national patient organizations concerned with Inflammatory Bowel Disease (IBD) – agreed to arrange a 1-day meeting to review the issue of transition in IBD. The key professional associations – the British Society of Gastroenterology (BSG), British Society of Paediatric Gastroenterology Hepatology and Nutrition (BSPGHAN) and the Royal College of Nursing (RCN) Gastroenterology and Stoma Care Forum – agreed to join NACC and CICRA in forming a steering group to arrange the meeting.

The meeting was held at the Royal Society of Medicine, London, on 16 June 2005 and was attended by 60 invited healthcare professionals, patients and parents. The healthcare professionals were from both paediatric and adult services, and included doctors, nurses, dieticians and psychologists. There were also representatives from the Department of Health and from a commissioning authority.

The day was structured around presentations of the various perspectives in the morning, followed by working groups on three key areas in the afternoon. The aim was to explore problems and strategies in supporting transition, but it also became clear that there were significant issues concerning the provision of suitable care for adolescents which were broader than the transition from paediatric to adult care.

Given the limitations of a 1-day meeting, it was not possible to discuss and reach agreement on specific recommendations. The objectives of this report are to provide a clear record of the presentations and discussions on the day, and to highlight some of the key issues raised. Feedback from a wider audience – professionals and patients – is welcomed, via the website www.ibdtransition.org.uk, which we hope will become a means to share ideas and good practice. Meanwhile, the Steering Group will consider how best to take forward the issues already raised.

We would like to thank the following companies for the educational grants that made the meeting possible – Procter & Gamble Pharmaceuticals Ltd, SHS UK Ltd, and Nestlé Clinical Nutrition Ltd – and Stella Leigh for undertaking the extensive administration for the meeting.

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Contributors

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Speakers

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Sponsors

This meeting was initiated by the UK-based patient organizations and charities NACC and CICRA, to explore the issues of IBD from the perspective of adolescent patients, parents and healthcare professionals. The meeting was supported by the BSPGHAN, the BSG and the RCN Gastroenterology and Stoma Care Nursing Forum. The arrangements of the meeting were also supported by educational grants from Procter & Gamble Pharmaceuticals Ltd, SHS UK Ltd and Nestlé Clinical Nutrition Ltd.

**Meeting report compiled and written by Dr David Collison
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Explanation of abbreviations and terms

BSG: British Society of Gastroenterology – An organization founded in 1937, focussed on the promotion of gastroenterology within the UK, with representation within the British Royal Colleges and to the Department of Health and Government. It has over 2000 members, including physicians, surgeons, pathologists, radiologists, scientists, nurses, dieticians, and others interested in the field. Internationally, it is represented at both European and World level.

BSPGHAN: British Society of Paediatric Gastroenterology Hepatology and Nutrition – A society that provides professional leadership and promotes standards of care for children with gastrointestinal, liver and nutritional diseases. BSPGHAN supports research, training, and education of its members in order to help develop standards of care and implementation of child-centred strategies for the treatment of children with gastrointestinal disorders.

CICRA: Crohn's in Childhood Research Association – A registered charity that is dedicated to creating a wider understanding of Crohn's Disease and Ulcerative Colitis, particularly as these affect children and young adults. CICRA provides support for sufferers and their families, and raises funds to support approved medical research aimed at finding more-effective treatments and an eventual cure.

Clinician – A healthcare professional, such as physician, psychiatrist, psychologist, or nurse, involved in clinical practice, as distinguished from one specialising in research.

DGH: District General Hospital – General hospitals specializing in secondary care, throughout different regions of the UK. DGHs provide relatively short-term treatment to patients with a certain condition, who have been referred by a primary care healthcare professional.

DoH: Department of Health – The government department with overall responsibility for health and personal social care. The DoH is responsible for making changes in the NHS and social care, as well as improving standards of public health. The DoH is responsible for setting health and social care policies and standards in England, and modernizing all areas of the NHS, social care and public health.

EFCCA: European Federation of Crohn's and Colitis Associations – EFCCA was established in 1993, and its aim is to improve the wellbeing of patients with inflammatory bowel disease and their partners and families, through: working with and for the EFCCA Member National Associations and others throughout Europe; facilitating the exchange of information and the promotion of cross-frontier activities; effecting regular contact with the European authorities, doctors, health professionals and organizations, and with others world-wide; and the encouragement of scientific research into the causes and treatment of Crohn's Disease and Ulcerative Colitis (IBD).

GP: General Practitioner – Primary-care doctors who provide family health services to a local community. They are usually based in a surgery or GP practice, and are often the first port of call for most patients with a concern about their health. GPs refer patients who require specialist help to hospital consultants. GPs are not usually employed by the NHS, but provide services to patients through a contract with the Health Service.

HCP: Healthcare Professional – Individuals involved in the care and treatment of patients.

MDT: Multi-disciplinary Team – A group of clinicians, nurses and other health professionals, representing several different professional backgrounds, who all have different areas of expertise, and work together to deliver care to patients.

MCN: Managed Clinical Network – Linked groups of healthcare professionals and organizations, working in a coordinated manner by sharing information and resources, to ensure that high-quality, clinically effective services are being provided.

NACC: National Association for Colitis and Crohn's Disease – A registered charity with approximately 30,000 members in the UK, which brings together people of all ages who have inflammatory bowel disease (Ulcerative Colitis or Crohn's Disease), their families and the healthcare professionals involved in their care. There are approximately 65–70 regional NACC groups in the UK, which arrange educational and support meetings, publicity, and fundraising. NACC provides support, guidance, information, articles and funding for research.

NSF: National Service Framework – NSFs set national standards for healthcare, define service models for a specific service or care group, and set up programmes to support the implementation of those standards and models. NSFs are designed to improve the quality and cost-effectiveness of health services, and ensure that each patient receives the same

level of care. These standards are evidence based and define what patients can expect to receive from the NHS in major care areas or disease groups. The main aims of NSFs are to improve performance and decrease geographical variations in care standards. NSFs also establish performance measures, against which progress within an agreed timescale is assessed, and which are continually being developed.

PCT: Primary Care Trust – Health services in the UK are divided into ‘primary’ and ‘secondary’ services, and are provided by local NHS organizations called ‘trusts’. PCTs are locally managed, free-standing, primary-care NHS bodies, responsible for improving health, and commissioning and providing primary and community services that are accessible by local residents. PCTs make decisions about the type of services that hospitals provide and ensure that a high quality of service is being delivered. PCTs obtain about 75% of the NHS budget, and control funding for hospitals. There are approximately 300 PCTs in England, each one covering a separate district.

Primary, secondary and tertiary care – Primary-care services are those delivered in the community as part of the NHS, whereby GPs, community nurses and other healthcare professionals work to provide a first point of contact for patients, e.g. at GP practices, health centres and walk-in centres. Secondary-care services provide specialist care, typically in a local hospital setting, with patients under the care of a consultant, following referral from a primary or community healthcare professional. Tertiary-care services are provided by specialist centres (e.g. hospices that provide inpatient care) for the treatment of patients with specific conditions, who have usually been referred from secondary-care providers, such as district hospitals.

Executive summary

Inflammatory bowel disease (IBD) is becoming increasingly common in children, and adolescents now represent a significant group of patients with the disease. The inevitable transfer from paediatric to adult healthcare services can be a stressful time for chronically ill adolescents and their families, and there is an obvious need to establish an effective transition arrangement for this age group. There are substantial differences between adult services – which require a level of autonomy and independence on the part of the patient – and more-prescriptive, family-focussed, paediatric services. There are also differences in clinical management between paediatric and adult care, growth and puberty, and the availability of treatment options – for example, the importance of diet in the management of IBD in adult care is often not fully explored. A transition programme would provide adolescent patients with a continuum of developmentally appropriate care throughout adolescence to help prepare them for transfer into the adult service. Although ‘handover’ clinics were initiated in the 1980s, there is still no dedicated network for adolescents with IBD.

Objectives of the meeting

- ◆ To raise awareness of the issues affecting adolescent patients with IBD, their families and healthcare professionals (HCPs)
- ◆ To explore the problems and strategies associated with implementing a successful transition service, through a combination of presentations and workgroups

Resource requirements of a transition service

- ◆ Education and training should be provided to specialist HCPs in both paediatric and adult teams to help promote an integrated transitional service and allow the development of management styles appropriate to this unique period in a person’s life
- ◆ Increasing the frequency of communication between paediatric and adult teams would be an effective way of utilizing services that are already available, rather than having to initiate and resource an entirely new service
- ◆ Adequate preparation of patients and their parents will facilitate a successful transition period by encouraging patients to be more independent and take responsibility for their own illness

- ◆ Patients should have access to resources that provide consistent information concerning IBD, the process of transition, treatment options, and the availability of forums and facilities
- ◆ Developing lines of communication between patients, parents, HCPs and schools through e-mail and/or telephone is important in the management of IBD; however, issues of patient confidentiality must be taken into consideration
- ◆ The transition process would ideally start in early adolescence, and should incorporate health education
- ◆ Transfer should not be thought of as a single 'event', but as an adaptive process that takes place over a number of years to build trust, confidence and compliance by gradually introducing a patient to an adult team
- ◆ The age at which a patient is transferred to adult services should depend on the developmental, rather than chronological, age of each individual

Initiating a transition service

- ◆ A proposed model for a transitional service would be a multidisciplinary adolescent clinic or ward area in each hospital, run by a managed clinical network (MCN) and attended by both paediatric and adult teams. In reality, this option is not available to all patients because of geographical/regional constraints; the service has to be flexible to accommodate the variation that exists between patients, families, hospitals and funding opportunities in different regions
- ◆ Many of the issues facing adolescents with IBD are shared by adolescents with other diseases. Therefore, problems of IBD in adolescence could be addressed as part of a generic mixed-condition adolescent service that includes other gastroenterological or chronic diseases
- ◆ In view of the current structure of healthcare and financial restrictions, dialogue between patients, parents, HCPs and Government Commissioners is essential to discuss issues of funding and options for a cost-effective transition service

Future development

Two main areas for future work were identified from the participants' feedback:

- ◆ Further development of transition practice
- ◆ Work on the organisation of an adolescent service

Full report of the meeting

Main objectives of the meeting

- ◆ To explore problems and strategies in supporting the transition of adolescent IBD patients from paediatric to adult care
- ◆ To raise awareness of the issues for adolescent patients and HCPs and suggest possible strategies as ways forward to ease the transition

The inflammatory bowel diseases comprise, for the most part, two chronic relapsing and remitting diseases of the gastrointestinal tract – Crohn's disease (CD) and ulcerative colitis (UC). In some instances, these diseases have overlapping clinical and pathological features [1]. UC affects around 1 in 600 people in the UK, and CD 1 in 1200; it is thought that IBD is becoming more common.

The aetiology (the cause of the disease and the process by which it develops) of IBD is unknown, but it is probably due to a combination of genetic and environmental factors. There is a huge ongoing research effort to clarify the genetics of IBD and identify patients who are at risk of developing the disease. It is hoped that genetics will have a major impact on IBD management in the future. The aim of treatment is to induce and maintain remission (the period during which symptoms subside), and prevent relapses. The main treatment options in the management of IBD include enteral feeding, steroids to reduce inflammation, immunosuppressive agents and surgery.

CD is characterized by inflammation of one or more areas of the digestive tract, with unaffected areas of the gut in between. This may lead to ulceration, abscesses and strictures in the bowel. It can occur anywhere between the mouth and anus, but most commonly in the large and small intestine. UC is inflammation of the colon (large bowel), which causes ulceration and bleeding. Collectively, IBDs produce a range of gastrointestinal and extra-intestinal symptoms, including persistent diarrhoea, rectal bleeding, abdominal pain, weight loss, skin and eye disorders, and delayed growth and sexual maturation in children [2]. These symptoms can have a great impact on a patient's quality of life, well-being and capacity to function. Importantly, patients generally require lifelong treatment because IBD is chronic (a disease of slow progress, long duration and without medical cure) and typically has an onset before 30 years of age.

IBD appears to be increasingly common in children, and patients are developing the disease at earlier ages [3]. The physician treating children with IBD is confronted with a number of specific problems, such as the potential IBD-induced compromise of growth and weight, which may affect the onset of pubertal development and final adult height. The process of 'transitioning' an adolescent with IBD from a paediatric clinic to an adult clinic requires an understanding of the specific issues and challenges that confront the patient and HCP. Although 'handover' clinics were established in the 1980s, there is still no dedicated network for adolescents with IBD.

Speaker sessions

Adolescent Specialist: Professor Ian Sanderson

Summary

Although common elements of IBD are shared by paediatric, adolescent and adult patients, the style of management for adolescents with IBD should reflect this unique period in a patient's life. Care for adolescents during this 'transitional' period should be recognized as being at least as important as paediatric and adult care. Transition clinics should aim to bridge the gap between the family-centred paediatric service and more independent adult culture.

- ◆ Certain aspects of IBD are shared by adolescent patients and their paediatric and adult counterparts, including epidemiology, clinical disease, and drug treatment and surgery. However, the context and style of management in adolescents with IBD is fundamentally different, owing to the onset of puberty and the different presentations of IBD observed in adolescent patients
- ◆ The physical effects of IBD, including delayed or impaired puberty and a lack of growth spurts leading to short stature, can cause psychological problems: development of egocentricity; adoption of a 'sick role'; impaired sense of sexual or attractive self; and impaired development of cognitive functions and information planning. This may lead to:
 - ◇ Poor adherence to treatments and poor disease control, because of exploratory (risk-taking) behaviours; rejection of medical professionals as part of separation from parents; and poorly developed 'abstract' thinking
 - ◇ Social problems, including a sense of isolation due to symptoms of the disease and side-effects of the medication; reduced independence; and failure of peer relationships and education or vocation
 - ◇ Associated health-risk behaviours: chaotic eating habits resulting in poor nutrition
- ◆ It is important to recognize that adolescents often prioritize peer-group relationships over others, and can be rebellious towards parents' and doctors' advice

Recommendations

During a consultation

- ◆ It is advisable to see young patients by themselves, as well as with their parents, during a consultation
- ◆ The confidentiality of the patient should be assured
- ◆ A non-judgemental approach is essential, especially when discussing sensitive issues such as substance abuse
- ◆ The doctor should 'be himself', without trying to be 'cool' – young people want the doctor to demonstrate a level of authority, rather than trying too hard to be their friend
- ◆ Communicate and explain concepts in a manner appropriate to the patients' intellectual and emotional development
- ◆ For young adolescents, 'here and now' concrete examples should be used in favour of abstract 'if...then' concepts and discussions [4]

Bridging the gap

- ◆ Transition clinics should aim to bridge the gap between paediatric and adult culture
 - ◇ The paediatric treatment paradigm tends to be family centred, developmentally focussed, and ignores independence and increasingly adult behaviour in adolescents
 - ◇ Adult medical culture acknowledges autonomy, reproduction and vocations, while ignoring growth, development and family concerns
 - ◇ It is important to recognize that many individuals actually present with IBD during adolescence, a temporal trait of this particular disease that distinguishes it from genetic diseases, such as cystic fibrosis, which are often diagnosed in early childhood. The provision of adolescent services should, therefore, also cater for those patients that are diagnosed during adolescence, rather than just those moving from paediatric to adult care.

IBD Specialist Nurse: Sarah Hawnt

Summary

It is important to accept that each patient is an individual, rather than just a 'case', and that a planned and structured 'Transitional Service' is an essential part of care. Successful management of adolescents with IBD should be overseen by a specialist multidisciplinary team (MDT) to address specific physical, nutritional, and psychological aspects associated with the disease. This approach should be in conjunction with local services or primary care to maximize patients' compliance with treatment. Gradually introducing a patient to an adult team allows the development of trust, confidence and compliance.

- ◆ It is important to recognize that each individual child, adolescent or adult with IBD is unique. Generalization is not an option because of the vast spectrum of disease activity and morbidity, the variation in patient maturity and the potentially negative impact of treatments on quality of life
- ◆ Key problems for adolescents with IBD include: pain and diarrhoea; growth retardation; drug side-effects (particularly steroids); compromised education; lack of independence; poor compliance with treatment (i.e. defiance against parents and doctors); worrying about relapse; tiredness; and explaining IBD to other people
- ◆ From a nursing perspective, the main challenges in treating adolescents with IBD include:
 - ◇ Resistance to taking current treatments: many patients with IBD are not prepared to retry a therapy, which may be due to concerns about effects on body image
 - ◇ Compliance, which can be related to resistance
 - ◇ Reduction in the patient's quality of life, associated with social, educational and long-term IBD treatment issues in adolescents
- ◆ A major challenge facing the patient, parent and nurse is choosing the most effective treatment with the fewest side-effects, and with which the patient will comply
- ◆ Transition from a paediatric to adult centre can cause anxiety for patients and parents, the level of which is usually linked to disease severity and level of dependence on the paediatric team

Recommendations

Choosing and administering the most appropriate treatment options

- ◆ Greater treatment options now offer more choice and benefits for adolescents with IBD, and better patient management methods for HCPs
 - ◇ Treatments include diets (polymeric and elemental), second-generation clinical therapy and improved surgical procedures
 - ◇ Research into improving treatments is ongoing and will lead, ultimately, to the development of revolutionary therapies, which will offer greater choice for patients with IBD
 - ◇ Medical science is investigating the reason for the increase in children being diagnosed with IBD, and whether it is simply a case of better diagnosis or a genuine increase in the incidence of IBD
- ◆ Treatments must be used safely, for the minimum amount of time and in conjunction with a monitoring system
 - ◇ Prescriptions in the community can be problematic and, therefore, planning and communication is essential between hospitals and primary care personnel
 - ◇ To help ensure that patients comply with nutritional therapy, communication between the dietician, nurse and other members of the MDT is essential
- ◆ The development of good relationships between the patient and doctor or nurse is vital to acceptability and, therefore, the success of treatments. In turn, successful treatment may promote independence
- ◆ Patients should be given the opportunity to receive counselling about possible side-effects of drugs, and it is especially important to negotiate with patients over the timing of treatments that have to be administered in hospital
- ◆ School attendance can be promoted by negotiating with teachers for the provision of suitable toilet facilities, rest periods and initiation of buddy systems (although it is important to maintain the privacy and dignity of the patient)
 - ◇ Medicines in school should be kept to a minimum, although enteral feeds should not present a problem – parents should liaise with staff and consider using a school nursing service
 - ◇ It is recognized that school trips are beneficial to education and development of independence, and should be encouraged with planning and negotiation
- ◆ Having a well-planned and structured 'Transitional Service' is an essential part of care:

- ◇ Gradual introduction to an adult team is preferable, to allow the development of trust, confidence and compliance
- ◇ A detailed history of medication from diagnosis is necessary, including treatments administered, and responses and side-effects to these
- ◇ Social history is also important as it may have an impact on disease activity and acceptability of treatments
- ◇ The necessary changes in responsibility for prescribing and monitoring should be planned, so that patients are not left between services
- ◇ The location of appropriate care provision and associated travel arrangements should be organized in advance
- ◇ Early discussions between HCPs and patients and their parents facilitate adaptation to the inevitable changes associated with moving from a paediatric to adult clinic

Questions

In terms of logistics, there are fewer paediatric gastroenterologists than adult gastroenterologists (approximately 1:4). Therefore, a wider choice exists for adults regarding where to go; so how are adolescent patients currently referred?

- ◆ Referral to large MDTs and a formal clinic is promoted, especially for 16–20 year olds, as this gives patients the same package of care. Links with local centres are especially important if there are issues with transport. Patients are guided to adolescent ‘handover’ clinics, where available, rather than to local clinics

What are the procedures for coping with a lack of communication from adolescents and young patients who deny anything is wrong with them?

- ◆ Patients are educated on the physiology of the gastrointestinal tract and shown how to recognize symptoms, thereby increasing their knowledge of the disease to promote communication

How many HCPs are involved at the Sheffield Children’s Hospital, and how are relationships with schools developed?

- ◆ There are 100–150 patients (0–18 years of age), two consulting gastroenterologists, one or two nurses, a dietician and a psychologist

- ◆ It is important to recognize that there is variation in the level of acceptance of IBD (and other diseases) between different schools. Meetings are arranged in schools, when required, between HCPs and teachers

Describe the general procedure, at present, for transferring a child to an adult clinic.

- ◆ Informal consultation with the patient about transition begins in the paediatric clinic, where the patient generally feels safer. This is followed by informal meetings in the adult department before transfer to the adult clinic

What happens when there is a regional split between paediatric and adult clinics?

- ◆ The location where the patient is seen depends on what is available in their region and the mobility of the patient and his or her parents. This question highlights the need to recognize the different requirements of each patient, and each adolescent in particular

Does the current service cut off automatically when the patient reaches 18 years of age? How should the transition be managed when the child leaves home for university – especially the relatively long period of time between hospital visits?

- ◆ There is some flexibility, but patients at 18 years old usually prefer to go to the adult clinic
- ◆ It is important to establish and maintain communication between patients and their families. Whether a patient stays at university if symptoms worsen is largely based on the severity of the disease, and ultimately remains the decision of the patient

Senior Dietician: Bethany Dalton

Summary

There is no doubt that nutrition plays an essential role in treating IBD in adolescents, but there are no guidelines or protocol on the use of diet in IBD. Research into the effects of good nutrition in adolescents with IBD is essential to increase the evidence base in this specific population of patients, rather than having to rely on findings from paediatric or adult patients. Patients should be educated about the benefits of prescribed diets and encouraged to take responsibility for the management of their IBD.

- ◆ Patients with IBD often do not know what to expect when transferred to an adult clinic, and the importance of nutrition is sometimes not fully explained
 - ◇ Good nutrition is necessary for the onset and development of puberty
- ◆ There are several challenges facing dieticians treating patients with IBD moving into adult care:
 - ◇ Nutritional evidence is based on paediatrics, rather than tailored to adolescents
 - ◇ Achieving/measuring the onset of puberty
 - ◇ Compliance with treatment
 - ◇ Patient confidentiality
 - ◇ Communication with the patient
- ◆ Challenges facing the patient include:
 - ◇ Having to learn new management practices
 - ◇ Integrating into a new MDT
 - ◇ Managing low self-esteem and coping with the feeling of isolation
 - ◇ Potential psychological problems
 - ◇ Accepting that surgery may be necessary
- ◆ Challenges for parents include:
 - ◇ Difficulty in giving adolescents independence
 - ◇ Having less control over the patient's compliance with treatment
 - ◇ Dealing with emotional strain, financial burden and potential family conflicts

- ◆ The Royal Liverpool has transitional group meetings twice a year for adolescents moving into adult care
 - ◇ Patients are able to meet the new care teams, including the dietician, and learn how their care will change
 - ◇ Dieticians explain the role of diet in IBD, thus allowing adolescents to gain an appreciation of the benefits of a prescribed diet
 - ◇ Patients are able to gain a sense of independence, and have a chance to voice their concerns and grievances with the rest of their team

Recommendations

Diet as a treatment for young adults with IBD – informing patients of the importance of nutrition

- ◆ A prescribed diet can often be as effective as other treatments in IBD. Prescribed diets should be seen as first-line treatment in IBD, but are often not recognized by physicians as being appropriate
- ◆ Patients should be given more choice about diet – especially adolescents, for whom it may be more practical than long-term corticosteroids
- ◆ Diet should also be offered by more gastroenterologists as an ‘authorized’ alternative treatment to drugs
- ◆ There are no guidelines or protocol at present on the use of diet in IBD
- ◆ Support from parents is invaluable for encouraging patient compliance with nutritional therapies, especially when an elemental or polymeric diet is required
- ◆ The development of transitional care presents challenges for both paediatric and adult dieticians. Good liaison is essential to address the knowledge gap that currently exists between the two groups
 - ◇ Variation between practices should be minimized, and a multidisciplinary approach is necessary
 - ◇ Research should be directed towards adolescent groups to maximize the evidence base
 - ◇ Talking directly to the patient, rather than the parents, during transition would help to encourage the patient to take responsibility for their own IBD management programme
 - ◇ The patient management approach adopted by the Royal Liverpool is not as common in other hospitals, but it is highly recommended

Questions

Some MDTs have a more paediatric feel, rather than an adolescent feel. Therefore, how are adolescents' needs dealt with?

- ◆ Depending on the clinical condition of the adolescent patient, liquid feeds may be withdrawn temporarily on special occasions, such as birthdays. Although the intake of food and alcohol is usually limited, HCPs recognize that sometimes a more lenient and diplomatic approach may be appropriate. Feeding tubes are not used in adults, but certain goals – such as weight targets – are set for patients to aim for

Although young children generally comply with liquid feeds, 17- or 18-year-old adolescents may not – how is this lack of compliance dealt with?

- ◆ It is essential to educate patients who resist liquid feeds that nutritional therapies are likely to improve their growth and height, and that non-compliance may result in more-severe problems. There is no doubt that adolescent patients respond well to nutritional therapies, and these are increasingly prescribed as first-line treatments

Are there any educational resources currently available that are dedicated to adolescent 'transitional' IBD patients? What is the advice given to patients who smoke?

- ◆ There are no specific educational resources for 'transitional' adolescents at present. The most useful information is obtained from leaflets aimed at paediatric and adult patients. A lot of the information that is particularly relevant for adolescents is usually given to them verbally
- ◆ Patients with IBD are advised to stop smoking, as this is a major cause of relapse for CD patients and has negative health consequences in all IBD patients

Psychologist: Kate Blakeley

Summary

The major role of the psychologist is to help bridge the gap that can sometimes exist between the patients, parents and MDT. Although cognitive capacity increases during adolescence, allowing patients to better understand IBD, this does not necessarily equip them with the emotional capacity to deal with the consequences of the disease.

Psychologists are sensitive about the 'transition' of patients from paediatric to adult MDT, and can offer solutions to overcome potential psychological difficulties that the patient may experience. Psycho-social groups provide the best environment to discuss the transition process with patients and parents, and encourage patients to take responsibility for their own IBD management programme.

- ◆ One of the key issues concerning adolescent patients with IBD and their parents and HCPs is how best to bridge the gap between dependence and independence
- ◆ The age at which the patient is diagnosed and the severity of the disease are critical factors, which can affect how patients deal with their own management of IBD
- ◆ Race or cultural issues in families can also play a role in determining what is expected of the adolescent with IBD throughout his or her education
- ◆ Patients with IBD can experience disruption to their schooling, and it may be difficult to achieve their full educational and social potential
- ◆ Peer influence tends to increase throughout adolescence, often at the expense of parental influence. Peers may act like parents (being both supportive and, in some cases, non-supportive)
- ◆ Adolescents with IBD may experience an increased concern about their appearance and body shape, especially with the use of steroids and following surgery
- ◆ Patients with IBD may be concerned about the physical effects of drugs – on fertility, for example. This may lead to a 'loss of self' – which psychologists are trained to recognize and help to provide solutions
- ◆ The main challenges for the psychologist include:
 - ◇ Knowing who (i.e. which HCP) to work with. This largely depends on who has referred the patient to the psychologist

- ◇ Who makes the decisions? In most cases patients are encouraged to take responsibility for their own decisions
- ◇ How best to manage the team. Are the beliefs of the psychologist being imposed on the patient unnecessarily?
- ◇ What to hand over, and to whom, at the point of transition to adult care
- ◆ The main psychological challenges that demand a huge emotional adaptation for an adolescent with IBD include:
 - ◇ Learning to live with the disease (i.e. gradual acceptance that it has lifelong consequences)
 - ◇ Understanding the limitations and potential side-effects of therapies, and the potential limitations imposed on career development
 - ◇ Patients may develop an attitude of denial towards the consequences of the disease, or refuse to acknowledge personal vulnerability
 - ◇ IBD can literally take over a patient's life, especially after a long time in hospital

Recommendations

Seeing the whole person

- ◆ HCPs need to recognize that there is a huge variation in adolescents with IBD. Each patient should be seen as an individual, rather than 'just another patient with IBD'
- ◆ HCPs should refrain from imposing their own cultural standards on adolescents with IBD, and accept that these vary widely between families. For example, an adolescent who is still living at home at 18 years of age may be perceived as lacking in confidence, when in fact many adolescents from Asian families tend to live at home for longer

Challenges faced by adolescents with IBD

- ◆ It is important to recognize that emotional and social issues are often related to absence from school and lack of contact with peers. Some adolescent patients with IBD may become resentful of their peers, and therefore regular liaison between patients, parents and school teachers is important
- ◆ Patients with IBD should be encouraged to become their own 'expert', and be given guidance on how to accept responsibility for making their own decisions on the management of IBD

- ◆ It is important to recognize that although increased cognitive capacity allows patients to understand the disease, this does not automatically equip them with the necessary emotional capacity to deal with the illness
- ◆ Parents need to recognize when it is time to 'let go', and start giving the adolescent autonomy. There may be a disparity in the perception of autonomy between the patient and parent
 - ◇ Parents also need to allow a young person to express their experience with IBD in their own way

Confidentiality

- ◆ One way in which HCPs can improve the management of adolescents with IBD is to give patients the option of more individual, confidential consultations without their parents being present

Questions

What is the impact on the psychologist and HCP when an adolescent patient moves on into an adult MDT?

- ◆ There is generally a sense of loss, because psychologists (and HCPs) may have assumed a 'parental role' and have usually built close relationships with the patient

Young patient's perspective: (1) Ramone Bellot (CICRA)

Ramone is 15 years old and was diagnosed with CD at 8 years of age. He has received several drug therapies over his 7 years with the disease, and feels that he has a good relationship, built on mutual trust, with his doctors and HCPs. Discussions about transition to an adult clinic have been initiated, and Ramone is being introduced to the new team once every 8 weeks. Ramone feels that he has become more mature through having CD, and although Ramone's mother has always supported him throughout his illness, he is beginning to take more of a role in the decision-making process.

Questions

What do you feel about having to see doctors for the first time, who you have not met before?

'It can be a bit annoying when new doctors ask the same questions again that I have been asked many times before.'

When discussing future plans, what concerns do you have about transferring to an adult clinic?

'I am concerned about whether or not I will see the people that have been caring for me during the previous 7 years.'

What role do you see for your mum in the future?

'At the moment, I would still like to have mum accompany me to the clinic every 8 weeks. Sometimes mum asks questions that I haven't thought of or am too afraid to ask. Mum also provides a backup, so things that are discussed are not forgotten.'

How long do you think your mum would like to keep going with you?

'Forever!'

CICRA is currently developing its Website; what would you like to see in the 'Cool Zone' for young people?

'A chatroom or postroom for people of a similar age to share their experiences of living with IBD, which would help to reduce the feeling of isolation.'

Young patient's perspective: (2) Helen Martin (NACC)

Helen was diagnosed with CD at 11 years of age, and is now 31. She went through the transition to adult care at the age of 16. Helen lost a lot of weight at the start of the illness, mainly because she decided not to eat in order to 'prevent' diarrhoea. After losing 2 stone in weight in 2 weeks, Helen was referred to a specialist at a London children's hospital and diagnosed, after a colonoscopy, as having IBD. During the course of her illness, Helen has received steroids, mineral supplements and anti-inflammatory treatments. At 15 years of age, Helen was admitted to a ward that was 'more suited to under 7 year olds', which made her feel slightly awkward. Having open visiting hours was an advantage, as relatives could come whenever it was convenient for them. Helen's consultant decided to transfer her to a London teaching hospital, but there was no joint consultation between the current and future consultants – which would have been extremely helpful. The first visit to the outpatient clinic in the new hospital came as a shock. The environment was so different to the paediatric clinic to which Helen had become accustomed, and there were no patients of her own age. Helen's major cause for concern about the transfer from a paediatric to adult clinic was taking responsibility for her own illness. For example, when surgery had become inevitable, Helen wished that her mother could have been there to offer support as she signed the operation consent form; however, her mother was unable to attend because of the strict visiting times.

Recommendations

- ◆ A meeting with both the current and future consultants would help ease the process of transition and would be a positive step forward to building up confidence in a new consultant. It is beneficial for patients to be in familiar surroundings, with doctors they know, as they are more likely to feel able to talk freely with the new consultant during the meeting
- ◆ A dedicated adolescent ward with unrestricted visiting times would be of enormous benefit to facilitate transition into an adult environment
 - ◇ The adolescent clinic could be a mixed-condition clinic, and would not necessarily have to be dedicated solely to patients with IBD
- ◆ In cases where the young patients request consultations without a parent being present, it may be helpful to use the services of a Patient Liaison or specialist IBD nurse who can provide confidential accompaniment
- ◆ Although e-mail is no substitute for personal communication, the use of online communication, or direct telephone helplines, between patients and their doctors and IBD

nurse would facilitate patients' access to immediate advice. For example, based on a description of symptoms in an e-mail, doctors could quickly assess whether patients need an outpatient appointment or whether a simple adjustment to a prescription would suffice

- ◇ Written and verbal communication is key to developing good relationships between patients and HCPs, and should be encouraged in both the paediatric and adult clinics
- ◇ Many patients in a similar age group have the same concerns about long-term use of drugs, fertility and body image, and prefer to discuss these issues within their peer group
- ◆ Parents are often curious to know the key outcomes following a consultation. A brief report could be produced for parents, which would highlight the main points of the consultation, such as changes in medication and test results, so that confidentiality agreements are not compromised. However, this would take place only with consent from the patient
 - ◇ This would allow parents to be absent from the actual consultation, while retaining a level of involvement

Parent's experience: Kerry Bowen (CICRA)

Kerry is the mother of George, who is nearing 18 years of age, and was diagnosed with CD when he was 10 years old. During his time with a paediatric gastroenterology team at a London teaching hospital, George has received enteral nutrition, steroids, mesalazine (Pentasa), azathioprine, infliximab and surgery. George has spent a considerable length of time in hospital, mainly because of poor wound healing, and both George and his parents feel that they have built up good relationships with the team. This has been facilitated by having a direct telephone line to George's consultant and specialist nurse, who could be contacted at any time. George is taking responsibility for the management of his IBD and Kerry no longer has to accompany him to the hospital for blood tests or infliximab treatment.

Recommendations

- ◆ Treatment in an adolescent ward, which could be extended until patients are post-university age, would be invaluable for IBD patients before they move on to the adult ward
- ◆ Very often, patients would only need to make a phone call, rather than a hospital appointment, to receive an answer to a query, and therefore it would be useful to have a direct point of contact with a dedicated IBD HCP at the hospital
 - ◇ Young patients living away from home, in particular, would benefit from a service such as this
- ◆ It would be useful for patients and parents to have access to a medical education resource that included general information on IBD, the different types of treatment for IBD and current up-to-date research in the form of published papers

Questions

Where is the best place to care for adolescents?

- ◆ A dedicated adolescent transition unit, which may be mixed-condition. The space for the venue is not really the problem, especially in a hospital, but it is important for the ward to consist of patients of a similar age

Consultant Paediatric Gastroenterologist: Dr Peter Sullivan

Summary

There is an obvious need for establishing an effective transition service for adolescents with IBD, which allows patients to be seen as individuals and take responsibility for their own care. Transition should be gradual to allow patients time to adjust from the nurturing and prescriptive environment of paediatrics to the more collaborative and investigational adult service. Adequate preparation and educational resources should be provided prior to transfer to minimize the patient's distress during this process. 'Handover' to an adult clinic should be done when the patient feels ready and the disease is in remission.

- ◆ The median age in the UK for diagnosis of IBD in children under 16 years of age was reported as 12.6 years, i.e. at the onset of adolescence [5]
- ◆ A delay of more than 1 year from the onset of symptoms to final diagnosis of IBD, has been observed in approximately 25% of patients [5]
 - ◇ This delay was due, in part, to doctors not accepting that IBD occurred in young people. Other diagnoses were made to account for their symptoms, including anorexia nervosa
- ◆ Paediatricians can relate to young people at crucial stages in their development
 - ◇ Paediatric gastroenterologists have an acute appreciation of how much chronic IBD can delay growth and puberty in childhood
 - ◇ In most cases, adult gastroenterologists do not have this appreciation because any IBD-related effects will already have taken place by the time they see the patient at post-16 years of age
- ◆ Adolescence is a period of increasing physical growth and sexual maturation, and is accompanied by the development of a sense of personal identity and the progressive acquisition of relative independence. An understanding of this important developmental phase is crucial to effective management of chronic disease in these young people
 - ◇ Chronic diseases, such as IBD, during adolescence affect the usual physical and psychological developmental processes, and have significant social and emotional implications, which may have repercussions on the patient's family members and education

- ◇ It has been reported that 60% of children with IBD had a psychiatric disorder (predominantly depression and anxiety), compared with 18% of a healthy control group [6]
- ◇ Adolescents tend to get increasingly self-conscious and concerned about image and body function, which may lead to poor communication and distrust between parent and child about disease activity and compliance with treatment
- ◆ Factors that young IBD patients rank as important issues affecting their quality of life include: medication; worries about flare-ups; disturbances in their weight and height; longevity of disease; low energy; pain; feelings of 'missing out' and 'unfairness' (e.g. 'why me?')
- ◇ Acknowledging these issues provides an insight into the hearts and minds of adolescents with IBD, and facilitates relationships with patients that are based on trust
- ◆ Very few IBD clinics have transitional centres available at present
- ◆ At the John Radcliffe Hospital, Oxford, adolescents are eased into standard gastrointestinal care through a joint consultation with the adult gastroenterologist, patient and parents
 - ◇ During this time, a decision is made regarding when the patient will be ready for adult care, and any issues that precluded this are addressed
 - ◇ The average age of patients at 'handover' is 16 years, and can range from 14 to 17 years. This process can be delayed until 18 years, if appropriate
 - ◇ The aim is to give young adults a sense of identity – they want to be seen as individuals and have a level of control over accepting what is offered to them
 - ◇ A further aim is to provide a sense of partnership in helping the patients take more responsibility for their care
 - ◇ An extract from the *House of Commons Select Committee on Health, Fifth Report* (1997) states:

'Adolescent health needs, in regard to both health promotion and treatment of sickness are given insufficient priority and lack focus, with poorly developed services. Services for adolescents should be given greater focus and priority. The transfer of young people, particularly those with special health needs, from child to adult services requires specific attention'

Recommendations

- ◆ Doctors need to recognize that the effects of IBD on growth are the cause of major psychological and treatment issues for young adults with IBD
- ◆ Management of adolescents requires a sensitive understanding of the psychological and emotional reactions to chronic disease
- ◆ A multidisciplinary approach is utilized routinely in paediatrics, and many adolescents establish a long-standing relationship with their paediatric gastroenterologist. One of the criteria for an adult service, to which an adolescent with IBD would be transferred, is that it should also have a MDT
 - ◇ A clinical nurse specialist is a crucial component of the MDT, and with whom young IBD patients also develop close relationships
 - ◇ Communication and further education of MDTs may be achieved, in part, by having regular multidisciplinary meetings in which clinicians contribute to the discussion of particular case studies that are presented
- ◆ It is important to appreciate that quality of life in adolescents with IBD correlates with the level of closeness with their parents and the level of support received from parents
 - ◇ Emotional functioning is more often predicted by family functioning and stress-coping strategies than by illness-related factors
- ◆ A lack of compliance can exacerbate the symptoms of IBD, which may necessitate escalation of therapy. Therefore, doctors need to be sensitive to issues that are responsible for non-compliance, and engage in creative problem solving and guidance
- ◆ From a psychological viewpoint, management of IBD in adolescents should aim to: enhance independence of the patient; give them the opportunity to take more responsibility for their disease according to age and development; allow them to actively participate in medical decision-making; and provide them with a good knowledge of the disease

Transition to adult service – key elements for an effective transition programme

- ◆ Transition can be a time of difficulty and distress for the adolescent patient and parents. However, to ease this problem, transition should be gradual – ideally a ‘shared-care model’
- ◆ Policy on timing of transfer is vital – final ‘handover’ should be at a time when the disease is in remission and when the patient feels ready

- ◆ There should be an adequate preparation period and educational programme, and a co-ordinated transfer process with good administrative support and primary care involvement
- ◆ There should be the minimum number of HCPs in the clinic when the process of transition is being discussed with patients, to create a suitable environment that will facilitate the discussion of sensitive issues
 - ◇ The question of whether the patient would still prefer to be accompanied to the adult clinic by a parent should be addressed, and is ultimately the patient's decision
- ◆ Transition should be recognized as being an adaptive process: from the prescriptive and nurturing environment that characterizes paediatric services, to more collaborative and empowering adult services
- ◆ Paediatricians should adapt their relationship to provide a more mature and integrative style of care as the child becomes an adolescent

Questions

The good relationship you have with the patient works both ways; how do you feel when patients begin transition to adult services?

'A sense of bereavement, loss, difficult to let go. As HCPs, we can appreciate and understand parents' dilemmas.'

There are approximately 200 people with IBD to every 100,000 of the population – how well do you feel that resources match requirements?

'There are approximately 190 young patients with IBD in my clinic. We aim to see those suspected of having IBD for their first consultation within 2 weeks of referral.'

Consultant Physician and Adult Gastroenterologist: Dr Ed Swarbrick

Summary

It is important to recognize that the developmental age, rather than chronological age, of a patient is often a more appropriate indicator of when a patient is ready for the transition to adult care. Maintaining communication between HCPs and patients is important for establishing trust and facilitating the transition process.

- ◆ When the ‘black hole’ of adolescence is combined with the ‘black hole’ of IBD, this amounts to a daunting prospect for any young patient
- ◆ Knowing when to initiate transition in young patients is essential: the biological and developmental age of a patient is often more important than actual chronological age
- ◆ At New Cross Hospital in Wolverhampton, there are two identifiable and committed individuals – an adult gastroenterologist and a paediatrician – to help the transition of IBD patients aged 12–16 years. There is also a peripatetic paediatric gastroenterologist
 - ◇ Children under 12 years of age are referred to the peripatetic paediatric gastroenterologist; 12–16 year olds are referred to both the adult gastroenterologist and paediatrician; those over 16 years of age have the opportunity to visit an adult clinic
 - ◇ This procedure is aimed at establishing trust between the patient and the two senior doctors, and helps to facilitate a comfortable transition
 - ◇ Children are also introduced to ‘friendly’ surgeons, so that young patients are made aware of the benefits of early surgery
 - ◇ At present, there are approximately 30–40 patients, in total, with IBD at New Cross, 10 new patients enrol per year, and five transition out per year

Recommendations

- ◆ Lines of communication between patients and HCPs should be established, maintained and made clearly available, especially after hours
- ◆ It may be beneficial for a doctor to establish communication with a school or university that a patient is attending or will attend in the future
 - ◇ The patient’s current doctor may consider establishing contact with a local specialist gastroenterologist who can offer support to the patient while he or she is away from home

Questions

Sensitive issues for adolescents with IBD include their sexual development, preoccupations and pregnancy – where can patients talk about these concerns?

- ◆ There is no straightforward answer to that. There may be some difficulty with vocabulary – adolescents sometimes lack the communication skills necessary to address these matters. To compound the problem, HCPs are sometimes not very good at discussing these issues either. However, these concerns also affect the majority of teenagers – not only those with IBD

Breakout sessions

Medical: Chair – Professor Peter Milla; Reporter – Dr Richard Pollok

Summary

‘Transition’ versus ‘transfer’

The aim of a transition service for adolescents is to provide a bridge between paediatric and adult services – ‘no transition, no transfer’.

Objectives of a transition policy

- ◆ To provide a service in which care can be transferred to an environment that is more appropriate for the specific age and developmental requirements of each adolescent patient with IBD
- ◆ To prepare patients for transfer and provide appropriate resources (e.g. information and facilities)

Issues related to transition service design – principles and resources

- ◆ Adequate provisions of ‘manpower’ to run an effective service
- ◆ Appropriate environment – location of a ‘transitional’ unit to accommodate patients with different needs
- ◆ Collaborative – identify to what extent this process involves primary care and General Practitioners (GPs)
- ◆ Variable duration of transfer – according to the needs of each patient

Standards and requirements

- ◆ A standard of care should be maintained from one service to the next
- ◆ Adequate provision of dedicated HCPs at either side of the transition process and a defined point of contact
- ◆ Establishment of a National Service Framework (NSF)

Conclusions

A ‘model’ service can be designed, but it must be flexible to accommodate the variation that exists between patients, hospitals, and funding opportunities.

Aims of the session:

- ◆ To define ‘transition’ and distinguish it from ‘transfer’
- ◆ To identify the objectives of a transition policy
- ◆ To discuss issues related to the design of a transition service
- ◆ To set out minimum standards and requirements for a transition service

‘Transition’ versus ‘transfer’

- ◆ ‘Transition’ is the phase that bridges the gap between paediatrics and adult care, in terms of age and development. It may also be considered as the period of time in which a young person moves from one to the other, by virtue of their age and development
- ◆ ‘Transfer’ is the handover of primary medical care responsibility during transition, i.e. where the lead paediatric care provider passes on responsibility for care to an adult team – care is moved from the paediatric to the adult arena
- ◆ Transfer should not occur without a period of transition
 - ◇ At best, policy statements can only provide guidance for best practice – geographical, resource and other constraints may restrict the number of patients who have access to transitional clinics in adult centres. Different solutions will inevitably benefit different places
- ◆ The transition process raises issues about new concepts and services

Objectives of a transition policy

- ◆ To provide a service in which care can be transferred to an environment that is more appropriate to the age – or more importantly, development (i.e. emotional and physical maturation) – of adolescent patients
- ◆ To address the specific needs of this age group, which is at least as important as preparing the individual for adult care. For example, preparing the patient to be independent, and encouraging autonomy through transition
- ◆ To provide information, facilities and an environment that is specific to this group

Issues related to the design of a transition service

Issues arose relating to a predominantly centralized paediatric service and localized adult care:

- ◆ Where should the 'transitional' patient be sent for their adult care, and who makes this decision?
- ◆ Should there be provisions for outreach services to take care to the patients?
- ◆ To what extent does this process involve primary care and, more specifically, GPs?
 - ◇ 'GPs tend not to have access to the necessary resources' (gastroenterologist)
 - ◇ 'GPs tend to shy away from writing prescriptions and responsibility – leave it to the IBD experts' (parent)
 - ◇ 'The nurse should really be the link to primary care' (gastroenterologist)
 - ◇ 'Specialist IBD nurses are part of the reason why GPs are by-passed, as patients can go directly to these instead' (gastroenterologist)
- ◆ The design of transition services should be planned, structured, flexible and collaborative, with adequate manpower (at all levels) to run effectively
- ◆ An effective relationship and liaison between care providers and the patient should be established, with clear lines of communication open and available for every situation in both the paediatric and adult services
- ◆ The duration of this transition process should be flexible according to the needs of each individual patient
- ◆ **Where should the service locate a new patient?** There are arguments for and against introducing new patients to paediatrics, adult care, and transition clinics – although no conclusions could be made at this stage. This question raises an important issue of 'location', which will need to be considered in the event of transition being established
 - ◇ The location must have adequate facilities to deal with an emergency

Standards and requirements

- ◆ No lowering in the standard of care from one service to the next
- ◆ Adequate preparations for transfer to adult care
- ◆ Adequate resources (MDT) at either side of the transition process:
 - ◇ Consultant paediatric gastroenterologist
 - ◇ Consultant adult gastroenterologist
 - ◇ Dedicated specialist nurse
 - ◇ Psychologist
 - ◇ Dietician
 - ◇ Stoma nurse
 - ◇ Medical secretary

- ◆ The paediatric gastroenterologist, adult gastroenterologist and IBD specialist nurse together should meet with the patient at least once before transfer
- ◆ Patient ownership of the process (especially in key decisions)
- ◆ An identifiable point of contact is essential, especially for patients leaving home for university, and there should be adequate provision of educational resources about the transition service
- ◆ Introduction to transition service ‘handover’ should be made in the patient’s own environment (i.e. paediatric department or ‘transition clinic’ in a hospital), but separate from paediatric patients
- ◆ Although the Commons Select Committee highlighted the need for adolescent care, and emphasized specific needs and concerns of this age group, nothing has been established to date. An NSF needs to be established for care of adolescents
- ◆ Concerns were raised over implications that suggest ‘transition’ may comprise two stages – ‘paediatric to adolescent’, followed by ‘adolescent to adult’. The ‘paediatric to adolescent’ move is an issue of providing a more appropriate environment and resources, such as psychological support and practical educational support

Questions

The physical environment of an adult ward can be intimidating to a young adolescent; would you agree that it is totally unacceptable to plunge adolescents straight into an adult ward?

A transitional/adolescent centre is most appropriate and should be set up in hospital to provide a more secure environment for young patients. It is a question of organizing the logistics and ‘space’ of a designated area – which doesn’t have to be large – because the adolescents are scattered throughout the hospital at the moment. All that may be required is a 4-bed bay or an 8–10-bed unit, depending on the size of service that is available at each hospital. Moreover, the facility could be designed to accommodate adolescents with other diseases as well, rather than solely for patients with IBD.

To what extent does adult gastroenterology require training in paediatrics?

It will be important to provide training to adult gastroenterologists, and especially ‘trainee’ adult gastroenterologists, about IBD in paediatrics to help provide an efficient transition service.

Psychological and Social: Chair – Susanne Wood; Reporter – Dr Julian Stern

Summary

Psychological requirements

- ◆ Psychologists need a developmental (at the level of the individual) and systemic (how the individual relates to other people) perspective
- ◆ Patients have psychological issues as individuals with IBD and as family members
- ◆ Psychologists need to appreciate how an illness can have an impact on the patients, parents and siblings

Psychological interventions for patients, their families and HCPs

- ◆ Each group could benefit from psychological intervention, but each would require different levels of support

Contracts

- ◆ A flexible contract between the patient and practitioners, before transition, would help to clarify issues of responsibility and confidentiality

Communication and confidentiality

- ◆ Any line of communication with the HCP is beneficial to patients and parents; however, issues of confidentiality may need to be addressed
- ◆ Forums allow families to meet people in a similar situation and ask questions of HCPs

Provision of information – to encourage early mention of IBD

- ◆ Information about transition, the differences between the paediatric and adult services, and the type of psychological support that is available should be made readily accessible to patients and their families

Conclusions and areas for further research

- ◆ Research to evaluate whether a contract is a viable proposition
- ◆ Investigate 'resilience' factors and coping mechanisms of psychologically stable patients with IBD
- ◆ Examine the psychological needs of IBD patients that seek access to psychological services after adolescence (e.g. in their 20s)

Aims of the session

- ◆ To determine how young people, parents and HCPs feel about the process of transition
- ◆ To identify and evaluate the quality of information and support that patients receive
- ◆ To examine areas that would benefit from improvement and/or development, in order to make transition a less daunting situation emotionally
- ◆ To evaluate the ways in which good practice can be encouraged and spread throughout the healthcare profession

Psychological needs and requirements

- ◆ Psychologists need to adopt both a developmental (at the level of the individual through the different phases in his or her life) and a systemic perspective (how the patient relates to other significant people in his or her life: parents, teachers, friends and HCPs)
- ◆ For example: a female patient is diagnosed with IBD aged 10 years, has menarche at 12 years of age, and has a proctectomy and a permanent stoma by 20 years of age. This patient will have her own psychological issues that affect her, as an individual IBD patient, and her family (i.e. parents and siblings)
 - ◇ It is important not to forget the effect that an illness can have on the patient's siblings – the feelings of neglect associated with parents appearing to give more attention to the sick child, and fears that they may also develop the illness at a later stage in their life
 - ◇ Parents need to recognize when to begin 'letting go' and give more responsibility to their children

Psychological interventions based on needs of the patients

- ◆ Various levels of psychological intervention are available depending on the needs of the patient. Assumptions should not be made about the type of support that may be required. Although the majority of patients are psychologically stable and resilient, other patients require more support. Should the psychological support be offered by HCPs, or be entirely voluntary through organizations such as NACC?
- ◆ Each of the three main groups involved in transition, including the patients, families and HCPs (Figure 1), could benefit from some level of psychological intervention and support. However, each group would require different forms of support
 - ◇ Psychological support should not be confined solely to the patient, as parents sometimes suffer psychological problems associated with their child's illness

- ◇ Psychological support could also be offered to the specialist consultant at the time of transfer, e.g. to ease the sense of loss
- ◇ It is important to ensure all parties have access to the necessary information and support

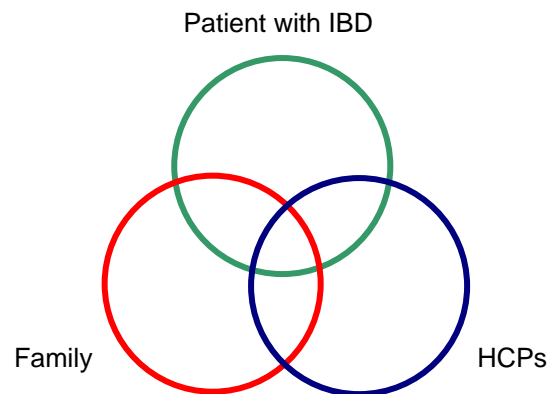


Figure 1. Transition is an interactive process between three main groups, all of which may benefit from different levels of psychological intervention.

Contracts

- ◆ Adequate planning is necessary at the transition stage, through negotiation and discussions between the patient, parent and HCPs
- ◆ A flexible contract could be agreed between the patient and practitioners before transition, which can be modified and updated. This would help to clarify issues on the level of support required, style of consultation (whether parents should be present or not), and communication and confidentiality (e.g. who should have access to information on blood test and colonoscopy results – should these go to the patient directly, rather than the parents?)

Communication and confidentiality

- ◆ It was considered important that a line of communication for patients and parents should be established with HCPs in both the paediatric and adult setting, regardless of whether clinicians preferred communicating by telephone or e-mail
 - ◇ Issues of confidentiality would be raised, however, if consultants communicated directly with the parents, rather than with the patients
- ◆ The patients in this session stated that they would prefer to discuss issues surrounding their IBD with their parents and doctors, rather than personal friends and other people in a similar situation – even through websites, e-mails and newsletters

- ◆ Parents also felt that communication with doctors and other parents of young children with IBD was vital
 - ◇ One parent was involved with an informal support network consisting of other parents who she had met on the ward, whereas another parent with outpatient appointments had not been given this opportunity
- ◆ At St Mark's Hospital, London, groups facilitated by staff are available for families to attend and discuss issues of IBD
- ◆ At the Royal Liverpool, Liverpool, and New Cross Hospital, Wolverhampton, open forum meetings, in conjunction with NACC groups, provide informal meetings for families. A panel of hospital staff is sometimes present to answer questions from patients and their parents
 - ◇ It was suggested that information may be provided more efficiently to families in formal, controlled forums
 - ◇ Care must be taken not to 'push' people into groups and force information on the young patient – 'enablement' is the key

Provision of information

- ◆ Patients and parents would find it useful to have more documentation available concerning the main differences between paediatric and adult clinics
- ◆ Liaising with both paediatric and adult services enables patients to receive relevant information about transition
- ◆ At present there is no consensus on how old a patient should be at the time of transfer from paediatric to adult services, although 'developmental' age of the patient is an important consideration

Areas that require further research

- ◆ Evaluation of whether a contract between the patient and HCP is a viable proposition
- ◆ Investigation of levels of psychological morbidity among IBD patients, 'resilience' factors and coping mechanisms of psychologically stable patients – in order to improve support for patients who require more psychological intervention
- ◆ Examination of psychological needs of those patients who only seek psychological support after adolescence (i.e. in their 20s), when they feel more reflective and introspective about issues that had occurred during their adolescence

Questions

Consultants often do not learn of problems with adolescents until they have reached their 20s and they can verbalize their needs. How do you translate these issues that you learn from a 25 year old into policy to address the problems of adolescents now?

- ◆ There is no substitute for physicians, surgeons, specialist nurses and other HCPs working closely with mental health specialists as part of the MDT
- ◆ For many patients, it is an issue of confidentiality – patients that have received a relatively secure upbringing are less likely to require confidentiality

Often parents feel that it is necessary to tell the doctor what is wrong when their child doesn't want to. How should this be dealt with, in terms of confidentiality?

- ◆ It is important that parents become involved in the consultation process; confidentiality is an issue that could be waived, as it is in the child's interest that parents should be present during consultancy

NHS Policy and Resources: Chair – Richard Jones; Reporter – Dr Charles Charlton

Summary

The aim of this session was to define the resources that are required to provide a successful transition service, rather than the actual acquisition of those resources

Issues relating to transition of patients with IBD

- ◆ Staff – establish an MDT comprising representatives from the paediatric and adult services, which meets for joint education and training purposes
- ◆ Patients and parents – need to have access to a reliable source of information on IBD and treatments, which is assessed regularly for quality and consistency. Young people may also want to receive information from their peer group; therefore, this type of information could be made available on the Internet

'Transition versus transfer' and adolescent care

- ◆ The focus should be on what the patients need; groups consisting of patients, parents and HCPs need to examine the level of service and the most appropriate care that would be required locally or regionally in their respective areas
- ◆ In an ideal situation, there should be the maximum choice available to patients and parents, and only care that cannot be provided locally should be provided centrally
- ◆ A 'model' for a transition service could be an MCN

Conclusions and requirements

- ◆ Identify the specific care needs of children and adolescents with IBD and act upon them. The cystic fibrosis trust, for example, has been a powerful lobby for improving care to this group for patients
- ◆ There is a need to develop adolescent (16–20 year olds) IBD clinics to help patients remain positive and allow them to develop responsibility for their illness – possibly as a joint initiative between paediatric and adult services

Aims of the session:

To discuss the main resource management issues for establishing a transition service, reaffirming what already exists and the areas that would benefit from refinement, including:

- ◆ Benefits of running the service as an MCN
- ◆ Resource implications of ‘transition versus transfer’
- ◆ Possibility of a mixed-condition adolescent service
- ◆ Education and training requirements
- ◆ Maintaining communication throughout the service

Running the service as an MCN

- ◆ Potential problems associated with a transition service may be solved by running the service that children and young people receive as MCNs – to provide the best-quality care, as close to patients’ home as possible
- ◆ An MCN should be facilitated, developed and supported by an MDT. This team could have a role in developing clinical services, research, and educational and training components of transition in IBD patients
- ◆ An example of an existing transition service is for diabetic patients
- ◆ One problem is how to include patients in smaller and more-remote hospitals in the UK (and Europe), which fall outside the present structure
- ◆ There is no firm evidence base at present that informs consultants on how best to manage each adolescent patient
- ◆ There are arguments for and against the construction of dogmatic statements that set the benchmark qualities of a service to which every institution must aspire
- ◆ The ‘model’ transition service should not only cater for the transfer from paediatric to adult clinics, but also for patients who are newly diagnosed *during* adolescence. The service should, therefore, have a general adolescent-based approach to the disease
- ◆ Information is provided in the *NSF Framework for Children* document (produced by the Department of Health [DoH]) about transition, the specific needs of adolescent patients and the standards that are required in a young person’s unit
- ◆ A link that connects policy, strategy and government is essential:
 - ◇ Can MCNs make adolescent units a reality?
 - ◇ Could an MCN cover all issues including the planning and delivery of a service?
 - ◇ Important considerations are equity and standards –what should the service include?

- ◆ The NSF in Wales is very different to that in England, it has 203 key actions – one of which states that there should be a young person's unit in all trusts. There is 'buy-in' from the cabinet in Wales; the question is whether all of the money is available. It is important that patients, parents and HCPs engage politicians and policy leaders by initiating dialogue. There are 17 children's specialist services, one of which includes paediatric gastroenterology, with specific standards stating that children need the best-quality care by trained people, and that children and young patients should be treated as close to home as possible (i.e. equity of access). For each of the 17 speciality services, the following are addressed:
 - ◇ Resources – the number of HCPs that are required in a team
 - ◇ Facilities – human and physical (i.e. space in buildings)
 - ◇ Referral pathways – children seen at diagnosis by paediatric gastroenterologists
 - ◇ Communication – provision of information for patients
 - ◇ Education and training – of members of the MDT
 - ◇ Transition
- ◆ A chapter for the Royal College on '*Tertiary Service Provision – a guide for purchasers*' sets out the requirements for a MCN to operate successfully. The difficulty is at a local level, which appears to be in a 'cost-neutral' situation
- ◆ In England, emphasis is being placed on distributing money for the National Health Service (NHS) down to the local level – HCPs need to make a case for adolescent services

Mixed-condition adolescence service

- ◆ Many of the issues facing adolescents with IBD are shared by adolescents with other diseases. Problems of adolescents with IBD could be addressed as part of generic adolescent services that cover a number of long-term conditions
 - ◇ How much overlap would there be between an adolescent service for IBD and one for diabetes, for example? The resource issues common to both diseases (such as the provision of a designated place where adolescents can be treated), as well as specific needs associated with each particular disease, have to be addressed
 - ◇ Disease-specific units may work in London because there are many hospitals and a relatively good public transport system, but may not be as successful in other locations in the UK

- ◆ It may not be practical to provide separate adolescent services in every hospital in the UK and, therefore, the needs of the patients should be assessed on a geographical/regional basis

Resource implications of transition leading to transfer

- ◆ Financial cost – a ‘transition service’ means integrating and using two services in parallel, utilizing the personnel from both the paediatric and adult teams
- ◆ Geographical constraints – it is wrong to assume that all paediatric patients in each hospital will have access to adult services at the same centre. If there are good adult MDT units with specialist nursing support in regional district general hospitals (DGHs), then it is likely that patients will not be transferred to the adult teams in large city hospitals
- ◆ Transition can involve an entire network of primary, secondary and tertiary services; the question is how to motivate people in each of these sectors to develop a patient-focussed service. The network would provide a framework built around the needs of patients and their families on an area or regional basis. A clinic for ‘shared-care access’ and an expert group – comprising patients, parents, DGH paediatricians from each unit, adult gastroenterologists, primary and tertiary carers, specialist nurses and psychologists – could also be established
 - ◇ It is important to provide patients and parents with ownership, so that there is strong input from the end users of the service
- ◆ There is concern that consultant sessions form a major part of the ‘currency’ of the NHS – where would the money come from?
 - ◇ It is not necessarily a question of consultant time, rather an organizational issue of consultants being able to see the patients locally. Thus, it is more an issue of having secretarial help and availability of space for clinics locally
- ◆ Auditing:
 - ◇ To identify the resources available in different regions of the UK, i.e. one ‘model’ is unlikely to fit all areas
 - ◇ To recognize strengths and weaknesses in the system

Education and training requirements

- ◆ Provision of easily accessible education and information resources for patients and parents
- ◆ Training of MDT – between specialist paediatric and adult teams – would be fundamental to the success of a transition service. For example, adult gastroenterologists would benefit from spending time in a paediatric environment
 - ◇ This concept could be expanded to other HCP specialists, including dieticians and psychologists

Communication

- ◆ The system should facilitate communication on all levels, between medical teams, smaller districts, families and schools. There needs to be vertical communication between paediatric and adult gastroenterology services, which may be achieved by combining paediatric and adult services in one department
- ◆ A potential policy area that needs addressing further is the level of liaison between patients, parents, HCPs and schools
 - ◇ There is some ignorance in the education system regarding adolescents with diseases; the patient's needs are sometimes not made clear to educational authorities

Questions

Adult gastroenterologists tend not to be trained in paediatric issues, unlike adult specialists in other areas, such as cardiology and neurology. What type of training is required to provide a successful transition service for IBD patients?

It would be a two-way process, with adult and paediatric gastroenterologists working together to provide a collaborative and integrated service. Adult IBD specialists would benefit from spending time in paediatrics, and *vice versa*. A transition service would also provide a good opportunity for adult dieticians, psychologists, and specialist IBD nurses to discuss issues surrounding IBD in adolescents with their respective paediatric teams. There is also a clear need for an increased number of specialist IBD nurses to help bridge the gap between paediatric and adult clinics.

Closing remarks and possible strategies for the future:

Chair – Professor Ian Sanderson

Ian Sanderson thanked everybody for attending and invited them to contribute their ideas on the feedback sheets provided.

Summary of Feedback

The management of adolescent patients with IBD will continue to require close collaboration between HCPs, including physicians, specialist nurses, dieticians and psychologists. As management becomes more complex, and options more varied, it is essential that the patient remains at the forefront of the decision-making process. Adolescent/young-person IBD clinics should aim to help the patient remain positive and feel in control. Most importantly, the patient must be viewed as an individual person rather than a 'case'.

Suggestions for the future, received from participant feedback forms, fell into two main areas, but there is obviously overlap between the two areas:

◆ Transition Practice

- ◇ Set up a transition service, which could be a mixed-condition clinic that includes patients with other gastroenterological or chronic illnesses
- ◇ Adolescent/young-person IBD clinics could be a joint initiative of paediatric and adult services
- ◇ Provision of information on the transition/transfer process and confidentiality issues for parents and patients over 12 years of age
- ◇ Information also made available on the Internet
- ◇ Develop lines of communication from parents [and patients] to HCPs in both paediatric and adult services, through e-mail and telephone. A telephone helpline with voicemail is an option
- ◇ Draft a 'flexible contract' to define the responsibilities of adolescent patients, parents and HCPs
- ◇ A more cohesive MDT approach in design and delivery of an adolescent service, with paediatric and adult MDTs working together

◆ Adolescent Service Organisation

- ◇ Provision of adolescent facilities in hospitals, which should include clinics and wards or ward areas

- ◇ Education/training for gastroenterologists, dieticians and psychologists in the management of adolescents with IBD
- ◇ Collaboration between paediatric and adult services; sharing of expertise and services
- ◇ Provision of additional specialist IBD nurses
- ◇ Identify psychological resource issues, including manpower, education, training and information for patients and parents
- ◇ Parent/patient/HCP small group meetings to set national standards and finalize guidelines
- ◇ Establish an NSF for adolescents and build MCNs that focus on specific needs of patients in each region
- ◇ Dialogue with Government Commissioners; establish a multi-stakeholder Working Group involving the DoH and the Department of Education
- ◇ In view of the current health structure and financial restrictions, funding issues and options for a cost-effective adolescent/transition service should be explored and discussed with primary care trusts (PCTs)
- ◇ Lobby funding bodies and increase publicity to highlight the need to establish a transition service

What should happen next – participants' feedback

The following is a summary of the feedback sheets distributed to participants at the meeting.

What do you think should happen next?

- ◆ In order to facilitate discussion and action, this meeting report should be distributed to the DoH, Commissioners, PCTs, BSPGHAN, BSG, parents, patients and those who attended the meeting
- ◆ Produce an NSF for adolescent services, setting out standards and guidelines for transitional care
- ◆ Lobby Government and PCTs for funding of transitional care units
- ◆ Joint actions for NACC and CICRA include:

- ◇ Review issues raised and agree an action plan to take the issues forward
- ◇ Provide individuals with feedback on the actions from the day
- ◇ Convert the issues raised into projects to be divided between NACC and CICRA, and publish a joint statement
- ◇ Promote a greater advocacy role for NACC, linking with professionals
- ◇ Review points raised at family group
- ◆ Lobby Committee of BSG regarding adolescent GI training and organize education days relating to adolescent issues
- ◆ Establish a DoH adolescent facility
- ◆ Pilot projects that would provide parents with more support, e.g. psychologically
- ◆ Set up regional working parties
- ◆ Produce literature in the form of a factsheet package that provides information for children and patients about the transitional process
- ◆ Agreement with formal groups, BSPGHAN, BSG, the Government and patient groups
- ◆ Promote the establishment of transitional inpatient/outpatient wards or clinics
- ◆ Read the Welsh Assembly documents on Paediatric Gastroenterology, Hepatology and Nutrition
- ◆ Continue discussions at professional national meetings, e.g. with BSG and Gastro-Nurse Forum
- ◆ Organize a larger meeting in order to report to more people
- ◆ Patients' groups are not wanted, but parents groups are
- ◆ Encourage a multi-stakeholder adolescent transition working group
- ◆ Undertake a research programme to investigate the precise requirements of young IBD patients and their parents
- ◆ Establish an Internet facility for the >12-year age group – this has also been requested by paediatric gastroenterologists in other European countries

Key issues that participants feel need to be taken forward

- ◆ Establish NSF standards and guidelines that enable a consistent approach to adolescent services to be undertaken
- ◆ Increase the provision of psychological support, accompanied by research into psychological resources and patient resilience

- ◆ More collaboration and integration between paediatric and adult gastroenterologists through MCNs to facilitate sharing of expertise and experience
- ◆ Joint education/training of adult and paediatric healthcare staff
 - ◇ Education of adult practitioners in areas of adolescent issues, particularly how IBD affects growth and puberty
- ◆ Engage and influence key local decision makers of the need to invest in local transition services
- ◆ Communication with parents and patients:
 - ◇ Parents and patients may be more inclined to ask questions of a clinician who adopts an informal approach, which would facilitate the development of trust that parents and patients have with their HCPs
 - ◇ The process of transition/transfer should be patient centred, involve an MDT, and happen at a developmentally appropriate time
- ◆ Communication at all levels:
 - ◇ Patients should be consulted regarding whether they would prefer parental involvement
 - ◇ Provision of a flexible means of communication
 - ◇ The importance of e-mail should not be underestimated, as it allows clinicians to provide patients and parents with prompt responses. Personal face-to-face meetings are generally time consuming and have to be booked in advance, while telephone conversations sometimes may be ambiguous
- ◆ Provision of information:
 - ◇ Patients need to receive adequate information on transition services and IBD in general
 - ◇ A 'contract' should be drafted that describes adult and adolescent responsibilities
- ◆ Resources:
 - ◇ The number of specialist nurses should be increased
- ◆ Facilities:
 - ◇ Provide an appropriate physical environment
 - ◇ Provide services in different regions
- ◆ Patients should be consulted on which network they would prefer to be associated with (i.e. not only NACC or CICRA)
- ◆ Incorporate adult gastroenterologists into MDTs
- ◆ MDT working together with patients

- ◆ There should be a continuity of care that is provided to patients during transition/transfer from paediatric to adult services, and the adult services that a patient receives at home and at university or work
 - ◇ Geography should not affect this continuity of care
- ◆ Review of organization of these services
- ◆ Better define the role of nurse specialists and other members of an MDT
- ◆ The difference between the regional paediatric service and local DoH-based adult service needs to be explained
 - ◇ There is widespread agreement on the need for transition clinics, but this difference could be a major limiting factor
- ◆ Provision of more transition clinics and adolescent wards
- ◆ Raise profile of gastrointestinal diseases in the DoH
- ◆ Provide support for patients, their families and MDTs through organizations such as NACC (by utilizing buddy systems, chat lines, training schemes and networks for parents)
- ◆ Provide nutrition and dietary information that is consistent and accredited
- ◆ Dialogue with government commission to establish a multi-stakeholder working group involving the DoH and Department of Education, which could take the recommendations forward
- ◆ A roundtable discussion between IBD representatives from BSG/BSPGHAN and surgeons. Similarly, discussions between the Royal Colleges and other specialities
- ◆ NACC/CICRA could propose a 1.5-hour paediatric/adult session at the annual BSG, which the European Federation of Crohn's and Colitis Associations (EFCCA) could also promote among the European Patients Societies

◆ **Feedback Score**

- ◇ The vast majority of attendees rated the meeting 'very useful' (Figure 2) (91.1% scored the meeting as 1–3; 66.7% scored the meeting as 1–2).

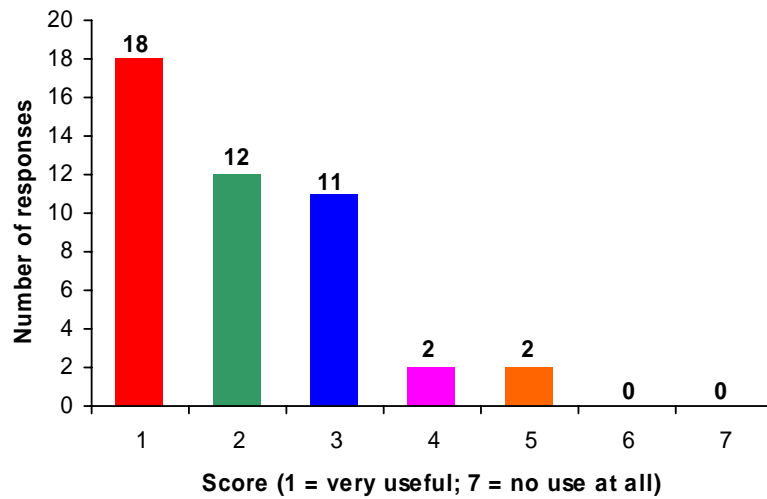


Figure 2. Rating of how participants perceived the meeting.

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Appendix: Meeting programme

Chairs for the day:

Professor Ian Sanderson, BSPGHAN; John Clarke, NACC; and Shirley Illsley, CICRA

| | | |
|----------------|--|---|
| 10.00am | Registration | |
| 10.30am | Introduction | Professor Ian Sanderson, BSPGHAN |
| | Adolescent specialist | Professor Ian Sanderson, BSPGHAN |
| | IBD Nurse | Sarah Hawnt, Sheffield Children's Hospital |
| | Dietician | Bethany Dalton, Royal Liverpool |
| | Psychologist | Kate Blakeley, Barts and the London NHS Trust |
| 11.35am | Tea/Coffee break | |
| | Young person's experience | Ramone Bellot, CICRA Helen Martin, NACC |
| | Parent's experience | Kerry Bowen, CICRA |
| | Paediatric gastroenterologist | Dr Peter Sullivan, John Radcliffe Hospital, Oxford |
| | Adult gastroenterologist | Dr Ed Swarbrick, New Cross Hospital, Wolverhampton |
| | Discussion and summary | |
| 1.00pm | Lunch | |
| 1.45pm | There will be three breakout groups, on the following topics: | |
| | Medical | – Chair Professor Peter Milla: how effective transition can be achieved. |
| | Psychological and social | – Chair Susanne Wood: provision of information and support for patients and parents. |
| | NHS policy and resources | – Chair Richard Jones: policy and resource barriers within the NHS relating to the care of adolescents and young adults, including training to work with adolescents. |
| 3.00pm | Tea/Coffee break | |
| 3.15pm | Plenary session | – Chair Professor Ian Sanderson: the reporter from each breakout group to feedback about the discussion in the group. There will then be a discussion about the feedback, and a summary at the end and a look at the way forward. |
| 4.00pm | Finish | |