



BRITISH SOCIETY OF GASTROENTEROLOGY

Care of Patients with Gastrointestinal Disorders in the United Kingdom

A Strategy for the Future

March 2006

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**Members of Strategy
Group**

AIMS OF THE DOCUMENT

The aim of this Strategy Document is to provide a robust support for the development and commissioning of Gastroenterology and Hepatology services in the UK. We envisage it will be used in business planning and service improvement in primary care at local Trust level and regional level. We also expect it to be an essential document in negotiations for improvement in service and future planning.

Dr M D Hellier – Chair

Dr J D Sanderson

Professor A I Morris

Professor E Elias

Dr J De Caestecker



PREFACE

This document has been evolving during a period of unprecedented change in the National Health Service. The degree of outsourcing of medical care to the private sector, patient choice and competitive market forces could not have been imagined at the outset of the work. To try and construct a system of Health Care delivery in gastroenterology against this changing background has been difficult. However, we now recognise many of these changes to be a *fait accompli*, whatever our views may be regarding the wisdom behind them. The objective of both the Government changes and recommendations we make must be the same, being better care for the patient. We hope that the principles put forward in this document can be applied through whatever structure of service delivery finally materialises. We have worked with these political imperatives in writing a strategy for delivery of gastroenterological and hepatological services.

It is important to emphasise that this is one of two documents. These documents are complementary and need to be considered together.

The first document, written by Professor John Williams' Unit at the Centre of Health Improvement Research in Swansea is a major database of Burden of GI Disease and Existing Service provision. It is a unique document and is a reference base of carefully evaluated data arising from extensive literature searches. It can be found on www.medicine.swan.ac.uk/giservicesreview

This, the second document, is an executive summary with recommendations based both on the Swansea document but also on consensus view and expert opinion drawn widely from stakeholders in delivery of gastroenterological services. It has been apparent that there is a serious dearth of good evidence based research data on service delivery. Were we to confine our recommendation to those areas where such data exists, much of gastroenterology would remain unspoken for.

Gastroenterology, perhaps more than any other specialty, covers a multitude of disciplines and it has proved difficult to ensure that all those involved in the care of patients with gastrointestinal disorders have had input into this document. We have done our best but suspect there will be those we have overlooked and for this we apologise. Nothing comparable has been produced for gastroenterological services before. This should be viewed as just the start.

We wish to point out that this is not a policy document and it is not within its remit to discuss political issues relating to service delivery. This will be the subject of a third document produced by the Council of the British Society of Gastroenterology.

Dr Michael D Hellier
Chairman, BSG Strategy Group

FOREWORD



This is the kind of document that through the unmatched experience and commitment on which it can draw, a specialist society is well able to prepare. The document is not at all for specialists alone. It is for anyone concerned to ensure that there are coherent unified services for the treatment and care of patients with problems of the gastrointestinal tract.

For a number of reasons it is more than timely; it is necessary. First, in the absence of other national guidance of such depth it provides a sound basis for effective commissioning and continued development of these major services.

Second, it reminds us of the complexity of services (not only in this field but in other specialty services too) the interdependency of many disciplines and elements of service and the need for coherent organisation and delivery to give patients the safe, high quality service they are right to expect.

Third, the document reiterates the need to integrate training with service delivery, including the necessary development of a range of high clinical skills in non-medical health professionals and the broader education and training needs across the service.

Fourth, it points as others have done to weaknesses in health services data, including research data on service delivery, and the need for better IT support for clinical care, quality assurance and audit – in essence the underpinning of meaningful clinical governance.

Implicit throughout the document is the crucial role of clinical leadership, in service organisation, development and commissioning, and always in advocacy for patients and as stewards for the quality and improvement of care.

The document does not stand alone. It is complemented by a searching review of the evidence, prepared by the unit headed by Professor John Williams at the Centre of Health Improvement Research in Swansea. Neither is it the last word, but it represents the most up to date statement of the key place of these services in the NHS today.

Professor Dame Carol Black CBE

President, Royal College of Physicians



This report draws on a wide range of evidence based expertise to support the development in commissioning Gastroenterology and Hepatology services in the UK.

Its origins lie in discussions at the Joint Specialty Committee for Gastroenterology and Hepatology, a joint venture between the Royal College of Physicians and the British Society of Gastroenterology.

These ideas were greatly enhanced and evidence based by Professor John Williams and his colleagues from the University of Wales, Swansea. Dr Mike Hellier, Chairman of the British Society of Gastroenterology Strategy Group and his colleagues then invested enormous drive, energy and time and consulted widely in order to incorporate expertise from all relevant groups.

The spirit of co-operation between the British Society of Gastroenterology and the Royal College of Physicians has been maintained throughout with the continued encouragement and support of Professor Dame Carol Black, President of the Royal College of Physicians.

This report provides a secure base for evidence based implementation of changes in clinical practice in order to enhance high quality patient care which is central to all our clinical activity.

Professor Robert N Allan MD PhD FRCP

Past President

British Society of Gastroenterology

ACKNOWLEDGEMENTS

Wide consultation has taken place in the preparation of this document and I am immensely grateful for the very many individuals and Committees who have given so generously of their time in advising and contributing to it. Some are listed under contributors at the end of the document but there have been far too many to list all and I hope those not mentioned will accept my general thanks.

However, there are those about whom I would like to make special mention. The project has been driven throughout by the BSG Strategy Committee. Dr Jeremy Sanderson, immediate Past Senior Secretary of the Society, has given endlessly of his time throughout the last two years. Professor Tony Morris and Professor Elwyn Elias have been the other major contributors to the writing group.

Professor John Williams and his Unit at the Centre for Health Improvement Research and Evaluation, University of Wales, Swansea, took on the challenge to write the major review upon which the Strategy Document is based. John has been a continuous source of wisdom and advice.

I am grateful to Professor Dame Carol Black, President of the Royal College of Physicians, who has supported the need for this document in its early stages in the absence of a National Service Framework for Gastroenterology and has given it her full support in various ways since.

Our secretaries, Nicola McLaren, Janet Isted and Susan Milroy, have dealt with hundreds of communications, letters and numerous draft copies and have committed a huge amount of time to this document. Without them it would not have been possible.

Di Tolfree and Chris Romaya of the British Society of Gastroenterology have supported us throughout in so many ways over the two years and I thank them most sincerely.

Finally, the project would probably never have come about had it not been for the imagination and drive of Professor Robert Allan, then President of the BSG, whose whole idea this was.

Dr M D Hellier
Chairman, BSG Strategy Group

KEY RECOMMENDATIONS

General Recommendations

- Patients' ready access to optimal care should be the overriding principle governing their management.
- Assisted self management by the patient should be an integral part of the care of patients suffering with chronic diseases. This requires patient education and the support by easy access to expert services.
- Many gastrointestinal disorders are common and have far reaching consequences which require a multidisciplinary team approach to patient care (eg alcohol induced disease).
- There should be close integration between primary and secondary care to provide a seamless delivery of care. This requires the development of care pathways and models of care for chronic diseases.
- The provision of best care for patients with gastrointestinal disorders must be through integration and cooperation between medical gastroenterologists and gastrointestinal surgeons.
- Clinical governance should be strictly applied to all aspects including the primary/secondary care interface.
- Primary Care Trusts should review the delivery of gastrointestinal services (GI) and ensure that consultations and diagnostic services are available locally, whenever appropriate.
- Specialist nurses play an important and integral role, particularly at the primary/secondary care interface and in education, telephone access, monitoring and patient support.
- Trusts and their clinical teams should review GI services and when favoured by efficiency and economy, services should be shared locally, eg Endoscopic Retrograde Cholangio-Pancreatography (ERCP), motility/manometry.
- Centralisation of some services is essential, eg complex liver disease, liver transplantation, complicated pancreatitis, home Total Parenteral Nutrition (TPN) and certain complex GI cancers. However, the move towards centralisation of services, as has occurred for cancer, will also tend to centralise surgical, radiological and pathological services with potential harm to services in the small and medium District General Hospitals where most of the care still has to be provided. For many such services, there is no evidence to support the benefit of such re-allocation and audits are needed to detect any detriment to the overall standards of care.
- It is crucial that skills and services required to provide acceptable standards of care are maintained at a secondary (local) level.
- An overwhelming finding of the review is an exposure of the paucity of good research or evaluation relating to initiatives in service delivery. It is our strong recommendation that this is systemically introduced and developed to inform future decision making.
- There is urgent need for better Information Technology (IT) support for clinical care in gastroenterology. Without this, the introduction of comprehensive quality control and audit would not be possible. The workforce and facilities must be funded to provide this service. The above proposals would enable an integrated approach to clinical research including multicentre trials of all novel and unproven methods. This should be an integral part of future gastroenterology.

Cancer Services

- Integrated multidisciplinary teams should be in place, led by appropriate clinicians and supported by a cancer specific co-ordinator.
- There should be appropriate specialist nurses to expedite the patient's journey through the pathway agreed by the Multidisciplinary Team (MDT) and cancer network.
- Agreed protocols of management and mapping of patient's journey should be in place.
- Two or more specialists are required in each cancer area, gastroenterology, surgery, radiology, etc.
- A full range of diagnostic methods are needed including endoscopic ultrasound and cross-sectional imaging, Positron Emission Tomography (PET) scanning, etc as appropriate.
- Participation in research trials should take place.
- Appropriate links with palliative care and social services should be in place.

Benign Upper Gastrointestinal Disease

- Management should be kept close to the patient and in particular a majority of patients with dyspepsia should be managed in primary care.
- Endoscopy for patients with dyspepsia should be practiced according to guidelines, targeting those requiring exclusion of more significant disease (see NICE/BSG dyspepsia guidelines).
- Test and treat strategies for helicobacter pylori are cost effective in young individuals and should be incorporated into dyspepsia guidelines.
- Diagnostic endoscopy for dyspepsia may be delivered in primary care by a GP specialist but the training and governance related to this should remain within the realms of the secondary care.
- Gastrointestinal Bleeding. Patients with acute upper gastrointestinal haemorrhage should be managed according to agreed guidelines and ideally within a specialist GI unit. All acute hospitals should have arrangements for out of hours endoscopy carried out by appropriately trained endoscopists and using optimal equipment and facilities for complex therapeutic endoscopy.

Functional Gastrointestinal Disorders (FGID)

- Encourage development of neuro-gastroenterology as a sub-specialty.
- Ensure education of doctors in understanding and management of FGID at both undergraduate and postgraduate level. Training should include special modules in neuro-gastroenterology (the basic science underpinning understanding of FGIDs).
- Ensure adequately staffed and trained GI physiology technicians in departments on at least a regional basis.
- National audit of GI physiology departments, establish standards and ensure evidence-based practice. Encourage compulsory training in basic GI physiological measurement techniques.
- More research into value of multidisciplinary approach to FGID in primary and secondary care.
- Integrated service provision at the level of primary care with emphasis on a multidisciplinary approach to management of patients with FGID. Referral to secondary/tertiary care might be for clarification of diagnosis and formulation of a management plan or for management of rare complex disorders.
- Research and develop effective self-management policies across the whole spectrum of patients with FGID.

Inflammatory Bowel Disease (IBD)

- Multidisciplinary care is essential and should bring together gastroenterologists, colorectal surgeons, radiologists, histopathologists, specialist nurses, dietitians and pharmacists.
- An IBD multidisciplinary team meeting should have similar priorities to the cancer MDT but should take place at a separate time.
- A gastroenterologist specialising in IBD is central to the service.
- Self management is appropriate for some patients but the needs of the IBD patient vary greatly – the IBD service should provide support for the range of care options including assisted self management, shared care with primary care and hospital care.
- IBD specialist nurses play an important and integral role, particularly at the primary/secondary care interface and in education, telephone access, monitoring and patient support.
- Multidisciplinary nutritional support should be integral to the IBD team.
- Adolescent IBD is best managed in transitional clinics involving adult gastroenterologists and paediatricians.
- Patient support groups should be involved in planning of local IBD services.

Hepatobiliary and Pancreatic Disorders

- Initial screening of blood test (liver function) abnormalities should be managed in primary care. Defined pathways will identify patients requiring referral to secondary care for diagnostic tests (eg liver biopsy) and treatment (eg anti-viral therapy).
- Endoscopy for patients with cirrhosis and portal hypertension should be practised and treatment instituted according to guidelines.
- Optimal management of patients with rare and complex liver and pancreatic disease involves multidisciplinary team work with close co-operation of gastroenterologists, surgeons, interventional radiologists, nurse specialists, nutritionists, pathologists and intensivists.
- Ideally all doctors who deliver treatment for liver and pancreato-biliary disease should be part of a defined clinical network, lead by a Centre, which collects auditable data on outcome, efficacy and complications.
- All patients should have timely access to the following hepatological services:
 - (a) Advice and support to patients through a liver support group or clinical nurse specialist.
 - (b) Advice and support for patients with substance misuse problems.
 - (c) Rapid admission and skilled management of variceal haemorrhage.
 - (d) The placement of a transjugular intra-hepatic portosystemic shunt (TIPSS) if indicated for variceal haemorrhage, diuretic resistant ascites or hepatic hydrothorax.
 - (e) Renal support if indicated for patients with the hepatorenal syndrome.
 - (f) Admission, diagnosis and management of severe acute, rare or complex liver diseases.
 - (g) Admission, diagnosis and management of hepatocellular carcinoma and cholangiocarcinoma.
 - (h) Basic work up and advice for patients who may need a liver transplant.
- Patients with complications arising from acute pancreatitis or chronic pancreatitis should be referred or discussed with a member of the specialist team at the pancreatic or HPB centre. Complex interventions on these patients should be carried out either at the centre or locally after discussion.
- At each DGH, there should be a designated upper GI contact, either a physician or a surgeon, who liaises with the centre regarding these patients as part of a managed clinic network for benign pancreatic disease.

- Endoscopic ultrasound should be available centrally when required.
- Patients with pancreatitis should have access to a specialist nurse and genetic services.
- Complex hepatobiliary surgery and liver transplantation will continue to be available in a limited number of designated centres with recognisable networking with all referring centres.
- Generally speaking, services should continue to be provided at three categories of hospital:
 - a) District General and University associated hospitals that have a gastroenterologist with a primary interest in liver disease.
 - b) Teaching hospitals and regional centres with a liver or pancreato-biliary unit that do not undertake liver transplantations.
 - c) Liver transplant centres.

Alcohol Related Gastroenterological Problems

This document supports the following recommendations laid down in the Royal College of Physicians' document "Alcohol related harm, the growing crisis – a time for action" (2001).

- Screening strategy for early detection of harmful/co-incidental hazardous drinkers.
- Early assessment of dependence severity by appropriate trained staff.
- Widely available protocols for the pharmacotherapy of detoxification.
- Readily available acute response from liaison or specialist alcohol psychiatry services for the management of patients undergoing complicated alcohol withdrawal.
- Assessment of the need for referral to on-going support services by appropriately trained staff with knowledge of local services.
- Provision of brief interventions for co-incidental hazardous drinkers.
- Provision of general staff education.
- Occupational policies for alcohol for all hospital health care workers, for example with respect to drinking at work.
- Close liaison with General Practitioners on discharge.

Each NHS Trust should have:

- A senior member of medical staff and a senior member of nursing staff to act as a focus for alcohol strategy and to support more junior members of staff.
- Senior psychiatric colleagues with an interest in the management of alcohol problems to act as the primary link between the acute hospital trust and local mental health services. This individual may or may not be employed by the acute trust.
- One or more dedicated alcohol health workers employed by and answerable to the acute Trust. The roles will include:
 - a) Implementation of screening strategies.
 - b) Detoxification of dependent drinkers.
 - c) Brief interventions in hazardous drinkers.
 - d) Referral of patients for on-going support – with access/knowledge about locally available non-statutory/voluntary agencies.
 - e) To provide links with liaison/specialist alcohol psychiatry.
 - f) An education resource and support focus for other health care workers in the Trust.

Nutrition

- Nutritional support should be an integral part of a gastroenterology service and all Trusts should have a Multidisciplinary Nutrition team.

Workforce

- This report supports the recommendation of the Royal College of Physicians “Consultants Working with Patients” (2004) for 1 WTE Consultant Gastroenterologist per 40,000 population.
- Delivery of optimal gastroenterology services requires a co-ordinated approach involving primary and secondary care teams. It follows that corresponding increases in manpower in other disciplines will be necessary to provide this service. To date, detailed manpower data is not available for surgery, nursing and primary care.

Chronic Disease Management (CDM)

- Re-designing and developing CDM is essential to provide patients with better care. A major part of the workload in gastroenterology relates to chronic disease.
- Devolving more care to primary care level, developing GP’s with Special Interests (GPwSI), closer integration of primary and secondary care are all essential for effective CDM.
- Education, training of all levels of staff development and agreed patient pathway/protocols of care are a pre requisite.
- MDT type working is fundamental to the success of CDM.
- CDM cannot be achieved without appropriate resources to fund education, training and workforce requirements.
- The above cannot be achieved without full information systems.

Endoscopy

- Compliance with Modernisation Agency service improvement programme, with capacity and demand assessment and process mapping.
- Communal waiting lists.
- Reduction in down-time of endoscopy rooms with backfilling of lists.
- Employment of non-medical, trained endoscopists to deliver basic diagnostic services.
- Use of Global Rating Scale to assess the quality of the service being offered.
- Full range of modern diagnostic endoscopy equipment with computerised recording of results, image capture and appropriate training facilities.
- Provision of Joint Advisory Group on gastrointestinal endoscopy (JAG) approved training for all endoscopists, by trainers who have completed JAG compliant Training the Trainers Courses.
- Appropriate training for all other endoscopy related staff using established competency frameworks, and in line with Agenda for Change.
- Planning for introduction of Bowel Cancer Screening.
- Compliance with all current BSG and other relevant National Guidelines.

Specialist Gastroenterology Nurses

- Trained nursing staff in each area looking after gastroenterology patients (clinics, wards, endoscopy units).
- Specialist Nurses in IBD, Stoma Care, Liver Disease and Nutrition as a minimum. Cancer Specialist Nurses are needed for Upper GI, Hepatobiliary/Pancreatic and Colorectal cancer, but whether these nurses are aligned with surgeons or physicians will depend upon the structure of the Multidisciplinary Team. In all but Upper GI Cancer most of their work is related to surgery, whereas in oesophageal and gastric cancer many patients do not undergo surgery and require different nursing skills. Each patient with complicated pancreatitis should have access to a specialist nurse within the pancreatic network.

- A programme of education and continuing professional development should be in place to support these nurses.
- Most leaders in the field do not think that nurse endoscopists should undertake only Endoscopy, but should have some other responsibilities such as related clinic duties.
- There is uniform agreement that Nurse Endoscopists should not also work as Endoscopy Assistants.

Medical / Surgical Interface

- Close integration between medical and surgical gastroenterologists is fundamental to good practice. Separate MDT meetings are required on a weekly basis both for cancer and non-cancer disorders.
- With the increasing incidence of benign and malignant gastrointestinal disease, manpower needs in surgery can be expected to increase in a way comparable to those predicted by the Royal College of Physicians for Gastroenterologists. At present, no manpower data relating to surgical gastroenterological requirements is available. However, increased appointments of surgeons are required to support centralisation of services, particularly HPB surgery and oesophago-gastric surgery.

Pathology Interface

Key areas that need development to ensure standards are maintained:

- Identification of the most appropriate way in which gastrointestinal pathology service can be provided on a national basis, both by general pathologists and specialist gastrointestinal pathologies.
- Development and promotion of reporting guidelines for non-neoplastic gastrointestinal disease.
- Determination of the workload implications with pathology departments, associated with new screening programmes.
- Promotion of the value of academic gastrointestinal pathology.
- Exploration of the potential value of videoconferencing and telepathology for specialist referral work and for input into remote multidisciplinary team meetings within hospital networks.

Radiology Interface

- Both diagnosis and management of patients with GI disorders depends heavily on radiological support. Integrated teamwork and MDT's are essential for best practice.
- The rapid increase in the development of interventional radiology has led to an acute shortage of GI radiologists. This critical manpower issue needs addressing.
- More multidiscipline research is needed into new techniques such as PET-CT, Magnetic Resonance Imaging (MRI) and tumour ablation.
- There has been a shift from surgical to radiological interventional treatment for the management of complications of liver disease. It is no longer possible to manage liver disease without specialist radiological support.

Clinical Physiologists in Gastroenterology

- Physiological measurement in gastroenterology is essential for the management of many benign gastroenterological diseases. The gastrointestinal workforce in physiological measurement needs at least to double in order to address the clinical governance issues and to enable the 18 week target to be achieved.

Dietitians

- Dietitians should be essential members of any gastrointestinal team, their input being required across a spectrum of primary and secondary care, home visits, GP clinics, hospital out patients and the wards.
- An increase in numbers of dietitians must parallel the increasing workload in gastroenterology.

Paediatric Gastroenterology

- Links with one of the paediatric liver units for the management of children and adolescents with liver disease should be available in each hepatology centre.
- Children with IBD should be looked after in an appropriate “child friendly” setting and by paediatric gastroenterologists.
- By virtue of its relative rarity in childhood, IBD is considered to require involvement of a tertiary service.
- Transitional clinics in which paediatric and adult gastroenterologists and their multidisciplinary teams participate are recommended for children with IBD.

Primary Care

- GI diseases form a significant proportion of a GP’s responsibility and many GI disease are managed exclusively in primary care.
- QOF is an important driver to improved standards, while PBC will be the key determinant of future service development.
- Care of GI disorders will increasingly be delivered according to care pathways and in ambulatory settings.
- GPs and GPwSIs are well placed to implement changes in guidance for the identification of GI disease and changes to established treatment protocols.

Training

There is now a need for sub-specialty training.


- Training “all round” Gastroenterologists is no longer a sustainable option in the long term.
Sub-specialty training is difficult when clinicians are also expected to input into the care of emergency medical admissions.
- Proposed progression to sub-specialty training could include three or four of the following:
 - a) Luminal gastroenterology.
 - b) Hepatology.
 - c) Advanced therapeutic endoscopy (this is likely to be linked to training in pancreato-biliary endoscopy, including ERCP and endoscopic ultrasound).
 - d) Academic gastroenterology.

All specialties would include an initial basic training in general Gastroenterology.

Academic / Research Gastroenterology

There is now a need to reaffirm the major role to be played by academic gastroenterology in the future of the subject through the UK.

- To ensure a future for academic gastroenterology, programmes for training need to be supported by the GI community, particularly in order to clarify the core curriculum for training of the future university academic gastroenterologists.

- 
- The BSG can support the development of future clinical academics in gastroenterology by encouraging students and junior doctors to engage in active research in gastrointestinal science with the support of the Society.
 - A mentoring programme for aspiring young clinical academics should be provided by the BSG.

INTRODUCTION

Background

In recent years, there have been huge pressures to change and improve the delivery of health care services. Certain services were chosen as priority areas by the Government and National Service Frameworks (NSF) written. These focussed attention and energy on those services and brought with them funding to implement the changes.

Gastroenterology did not attract Government attention, was not seen as a public priority and did not feature in the GP incentive scheme – Quality and Outcome Frameworks (QoF's).

In 2003, aware of the fact there was no National Service Framework for Gastroenterology or Hepatology services and the consequent disadvantage this created for the specialty, the British Society of Gastroenterology (BSG) saw the need to write its own "Service Document". The aim was to produce a document which could be used to negotiate the improvement in provision of services at Trust, Strategic Health Authority (SHA) and national levels and at primary care level and in the community. This would be a document representing the views of all professional organisations involved with the provision of Gastroenterological services, patients and Patient Carer Networks.

Without such a document the development of Gastroenterology Services would continue to be fragmentary, reactive and driven by uncoordinated Government initiatives potentially to the disadvantage of the service overall. This has proved to be a huge challenge in an ever changing health service.

For such a document to carry the weight necessary for re-structuring services it has to be underpinned by hard, evidence-based data. With this in mind the Society commissioned Professor John Williams at the Centre for Health Improvement Research & Evaluation (CHIRAL) at University of Wales, Swansea to research the data which would constitute the backbone of the document. His team has been working intensively during the last year to find and analyse all available data.

Their evidence-based review of the burden of disease, and the organisation and delivery of services is available at <http://www.medicine.swan.ac.uk/giservicesreview>. It is a separate report from which the strategy document has drawn data on which to base its recommendations.

The Society's strategy in addition draws widely on a range of existing service reports, surgical, hepatological, nutritional as well as College Manpower and Service reports. It takes into account consensus view and expert opinion resulting from widespread consultation.

There are many diverse and often conflicting Drivers for Change imposed by Government, the profession, public expectation and disease trends, to quote a few.

Those with most immediate impact have come from Government initiatives introduced with the aim of tackling a specific problem but not always with due consideration of the broader picture and consequent knock on effects.

Examples are:

- Clinical Outcomes Guidance Group on upper GI cancer (COG guidelines)
- Two-Week Waiting Time Directive and other targets set within the NHS Cancer Plan

Drivers for Change

- Diagnostic/Treatment Centres and Independent Providers
- Cancer Networks and Screening Programmes
- The National Service Framework for Children, Young People and Maternity services (which includes standards for adolescent transition).

From the profession, the formalisation of “Clinical Governance” has rightly led to the need for:

- Quality assessment of service delivery
- New evidence and guidance about the best care
- Development of standards and guidelines
- The need for better IT
- Guidelines for the management of children and adolescents with GI diseases (Commissioning Tertiary and Specialist Services for Children and Young People) www.bspghan.org.uk

Added to these are:

- Increased incidences of GI cancer and most GI disorders
- New technologies
- New treatments
- The European Working Time directive and Modernising Medical Careers
- More specific directives on training requirements (Joint Advisory Group on Gastrointestinal Endoscopy (JAG), Joint Committee for Higher Medical Training (JCHMT), Joint Committee for Higher Surgical Training (JCHST), colon cancer screening.
- The recommendations of the Wanless Report
- NCEPOD “Scoping our Practice” Report recommendations
- The new Consultant Contract
- Moving care nearer the patient
- Developing the Primary / Secondary care interface

From a survey of the BSG members, three disease areas were considered most important:

- Colorectal cancer
- Alcohol-related liver disease
- Inflammatory bowel disease

It is noteworthy that other areas, although ascribed lower priority, have high prevalence and high morbidities. For instance, functional gastrointestinal disorders (FGID) which result in a high morbidity for patients constitute 40% of all gastrointestinal referrals in the United Kingdom. Over and above this are the ever-increasing patient and public expectations.

NHS Imperatives

The Government continues to set targets and priorities in service delivery. Although in general these are not specific to gastroenterology, they do provide an opportunity for the development of gastroenterological services, a vehicle to which to harness gastroenterological services needs. These imperatives include:

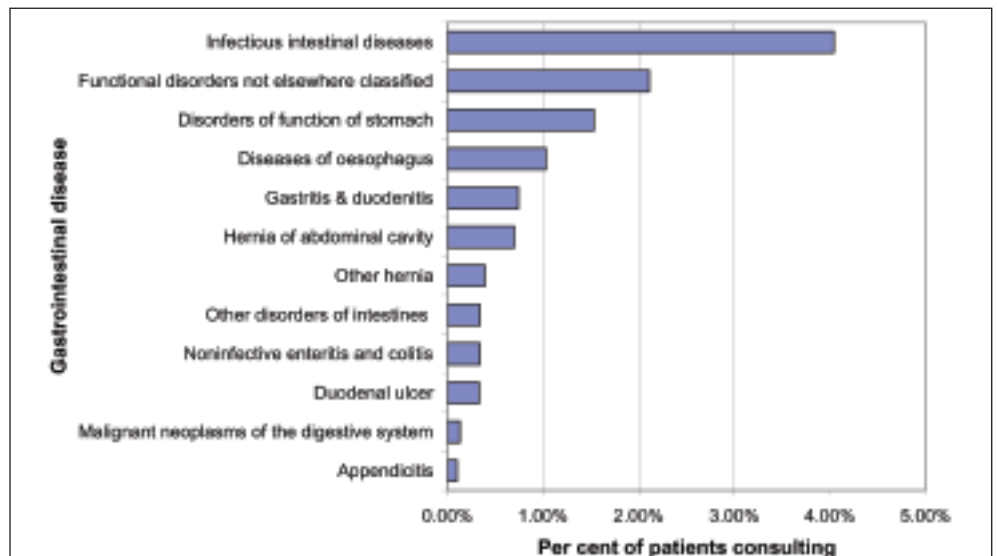
- 18 week referral to treatment target 2008. Most gastrointestinal work occurs in out patients and endoscopy and relates both to diagnostic work and chronic disease management. Those patients undergoing investigation and diagnosis fall within the 18 week target until discharged or treated. Optimal diagnostic services are essential to meet this target. This means endoscopy in the majority of cases.

- 62 day referral to treatment target for cancer. Once again, endoscopic services are crucial in delivering this target.
- Chronic disease management (CDM). It is now recognised by the Government that chronic diseases consume considerable healthcare resources and this has led to CDM being high on the Government’s agenda. Effective CDM can substantially reduce expensive in-patient and out-patient care and much gastroenterological work relates to managing chronic diseases, for example inflammatory bowel disease, chronic liver diseases. Improvement in chronic disease management is a high priority.

BURDEN OF OVERALL GASTROINTESTINAL DISEASE

The extensive review dealing with the burden of gastrointestinal disorders together with related issues by CHIRAL at the University of Wales in Swansea, has been described in the introduction.

In addition, there has been wide ranging discussion with selected experts and with all relevant providers of gastrointestinal services, patient groups and patients.

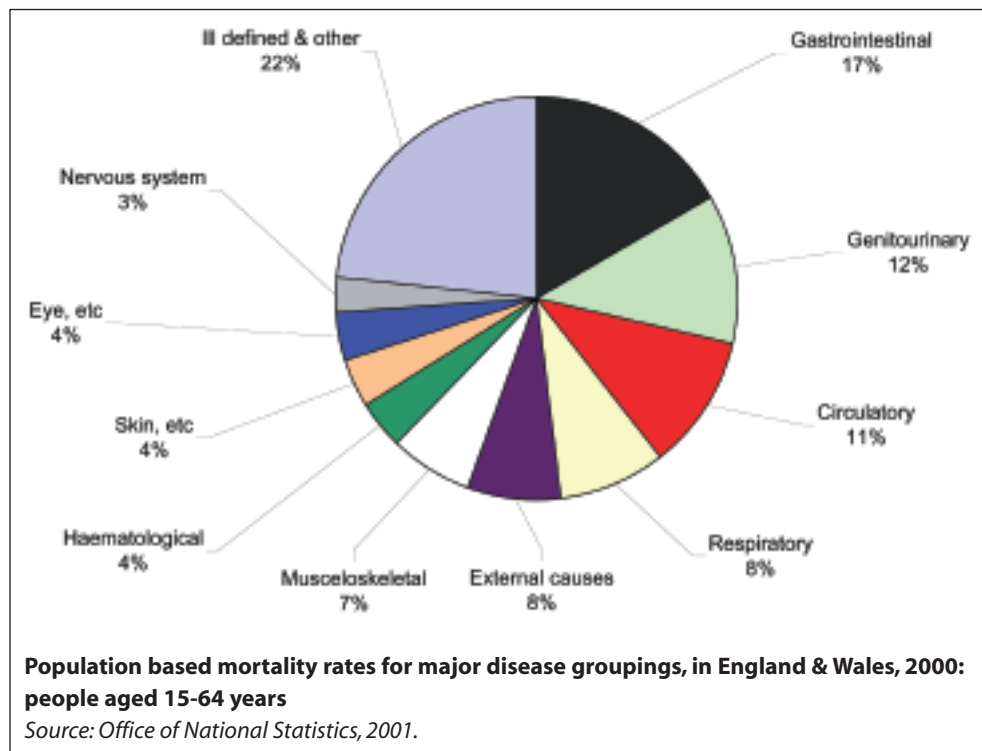


Percentage hospital admissions for major ICD-10 disease groupings in England, 1998/99-2001/2002: based on number of finished consultant episodes (FCEs)
 Source: Department of Health, 2004.

Overall Mortality Statistics

- Total deaths in England and Wales from all causes in 2000, 533,329.
- Deaths due to GI diseases 59,685 (11.2%)
- GI disease is the third most common cause of deaths after circulatory and respiratory causes. Deaths from diseases of the digestive system have increased by 25% in the last ten years.
- In the working population mortality is equal to respiratory disease.

Disease specific burden of disease is included under each section.



ECONOMIC IMPACT OF GI DISEASE (Per annum)

Non-NHS Costs

- 147,400 person years lost by those who die from GI diseases (between the age of 20-65 years) (Prism Study 1997)
- Estimated cost of early death from GI disease £3.23 billion (2004)
- 46,680 person years of lost productivity due to long term sickness absence from work (PRISM Study 1997)
- Estimated cost £1.05 billion (2004)
- 1/5th of all short term sickness due to GI disease
- Estimated cost £2.9 billion
- Total cost to British economy £7.18 billion
- GI morbidity and mortality clearly imposes major costs on the British economy

Costs to NHS (Excluding Cancer)

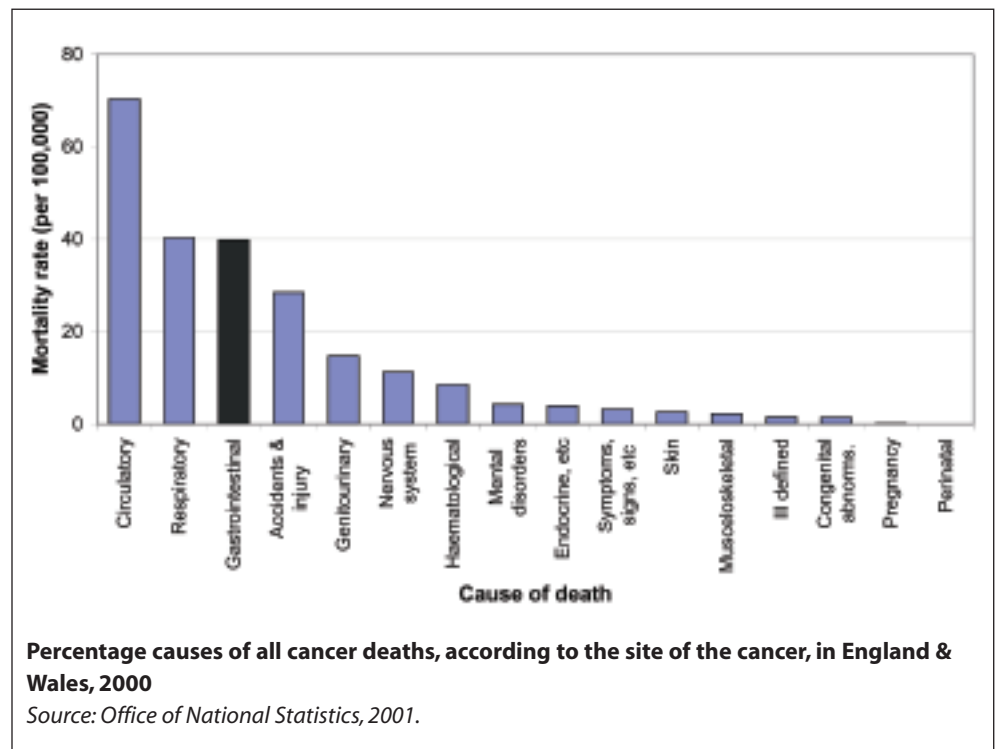
- Total Hospital Costs for GI Disorders 2001-2: £1.4 Billion
- Drugs: 60 million prescriptions for GI disorders (2002) - net ingredient cost of these drugs £802 million

Primary Care: Cost of GP consultations for GI disorders in UK (2001) £136 million (7.8% of all GP visits).

GASTROINTESTINAL CANCERS

Overall Statistics

- Commonest type of cancer in Europe.
- Colorectal cancer – third most common cancer in England and Wales 13.7% of all new cancers.
- Approximately 60,000 new cases of GI cancer per year, incidence rising
- GI cancers most common cause of cancer death of all major cancer groups
- 27% of all cancer deaths.
- GI cancers represent 25% of all male cancers and 20% of all female cancers.



Oesophageal Cancer

- 7000 new cases per year.
- Incidence 12 per 100,000.
- Incidence increased by 50% in the last 20 years.
- Five year survival 9%.

Gastric Cancer

- 10,000 new cases per year.
- 15% of all GI cancers.
- Incidence 17 per 100,000.
- 4.5% of all cancer deaths.
- 5779 deaths in 2000.
- Five year survival 12%. Much lower than Europe.

Drivers for Change

Pancreatic Cancer

- 6000 new cases per year.
- Incidence 11 per 100,000.
- Five year survival 2%. Worse than Europe.

Colorectal Cancer

- Commonest GI cancer.
- 30,000 new cases per year. Incidence increasing 55 per 100,000 for men, 40 per 100,000 for women.
- 39% of all GI cancer deaths, 14,000 deaths in 2000.
- Five year survival 36% men, 41% women. Lower than in Europe.

Liver Cancer

- 95% due to secondary spread.
- 2300 new cases of primary liver cancer per year.
- Incidence 4 per 100,000.
- Mortality rate increased by 50% in ten years.

There have been several major initiatives aimed at influencing the provision and improvement in GI cancer services, amongst these are;

Improved Outcomes Guidance

The guidance has aimed at rationalising service delivery for major surgery of many of the gastrointestinal cancers. Thus complex surgery is being planned on a population based basis, particularly for oesophageal, pancreatic and liver cancer surgery.

Although thought to be controversial by some authorities, Regional Cancer networks have been given the role of planning such service redesign.

Cancer Networks

Based on Strategic Health Authorities and supported by the main Cancer centres, these multidisciplinary committees are involved in trying to ensure equity of access for patients, uniformity of service delivery and management of all the major GI Cancers. The development of protocols, collection of standardised data sets and agreed service developments are other items covered by the Networks.

Training in Endoscopy

Although this might be seen to be peripheral to improvements in cancer services there has been general realisation that the standards of endoscopy and the service delivery have been poorer than required. Through two initiatives arising from the profession and funded by the National Cancer Plan, a National Endoscopy Training Programme has been developed and rolled out through 3 National and 7 Regional Centres. This programme of standardised courses, compliant with the JAG requirements for training, has been funded to the tune of almost £10M over a six year period and is due to run out in March 2007. The future of endoscopy training after that time remains an area of concern.

It has been appreciated by the Department of Health that endoscopy is a bottleneck in the delivery of the various targets that have been laid down, including the 2 week rule, 62 day rule for cancer (referral to starting treatment) and the 18 week rule. This has resulted in the DoH having a Diagnostics Division for endoscopy distinct from those for radiology and laboratory services.

Requirements for Optimal Service

Reduction in Waiting Times Secondary to Modernisation Agency (MA) Endoscopy Project

The MA introduced the Endoscopy Project, aimed at redesign of endoscopy services and improved service delivery. The roll-out of the project through SHA's with their endoscopy leads led by Dr Roland Valori has given rise to consistent reduction in waiting times and improved compliance with the 2 week rule for suspected cancer.

The development of a Global Rating scale for endoscopy has provided a means of assessing the quality of service to patients. This scale is to be expanded and refined to include a Training section as it has been appreciated that service and training are inextricably linked.

2 Week Rule for Patients Thought to Have Cancer

In many centres, the requirements for patients suspected by their primary care doctor of having a cancer has been achieved by undertaking gastroscopy or flexible sigmoidoscopy as the initial secondary care contact. Others have introduced one stop clinics combined with endoscopy. Although an efficient method of dealing with the referrals there is some evidence that it delays the investigation of non malignant conditions, in patients that can be seriously ill.

Introduction of Colon Cancer Screening

Although most Gastroenterological services provide surveillance for some groups of patients with an increased risk of cancer (Barrett's, IBD, Cirrhosis) until recently population screening has not been thought to be cost effective.

Colon cancer, the most common GI cancer, has a prevalence that justifies population screening. Two pilot studies in Rugby and Dundee have demonstrated the efficacy and practicality of faecal occult blood (FOB) screening followed by colonoscopy in the 2% that are positive.

It is the intention in England that screening will start in April 2006, with the age group 60-69.

Because of the risk of perforation and potential for subsequent death the screening program is to be rolled out in those centres with high achievement on the Global Rating scale, by colonoscopists who have been vetted and passed both a theoretical and practical test.

The intention is that the programme will eventually be delivered through 100 centres in England over the next three years.

- Integrated multidisciplinary teams lead by appropriate clinicians and supported by a cancer specific co-ordinator.
- Appropriate specialist nurses to expedite the patients journey through the pathway agreed by the MDT and Cancer Network.
- Agreed protocols of management and mapping of patient journey.
- Two or more specialists in each cancer area; gastroenterology, surgery, radiology etc.
- Full range of diagnostic methods including Endoscopic Ultrasound and cross-sectional imaging, PET scanning etc as appropriate.
- Participation in research trials.
- Appropriate links with palliative care and social services.
- Access to genetic services.

Other Issues

Cancer offers the paradigm for a quality service to deliver the best care for patients with the realistic prospect of improving outcomes by early detection, timely investigation and specialised care. All the above drivers for change have, and will, impact on the results. The need to integrate training with improved service delivery is only possible with process mapping of the patient's journey, capacity and demand assessment of service (particularly endoscopy) and in many cases expansion of capacity by appointment of Nurse Endoscopists.

GI HAEMORRHAGE

Upper gastrointestinal haemorrhage affects 80-170 per 100,000 population and results in significant mortality (remains as high as 15%).

Patients with acute upper gastrointestinal haemorrhage should be managed according to agreed guidelines and, ideally, within a specialised GI unit.

All acute hospitals should have arrangements for out of hours endoscopy carried out by appropriately trained endoscopists. This will require re-appraisal of manpower levels and in areas of scarcity mandate the appointment of additional consultants or the withdrawal of gastroenterologists from other rotas for provision of out of hours care.

Non-steroidal anti-inflammatory drugs (NSAIDs) contribute significantly to the burden of upper gastrointestinal haemorrhage resulting in an estimated £35 million per year of in patient costs.

The BSG has joined the National Blood Transfusion Service in a national audit of services for gastrointestinal haemorrhage. The results of that audit should inform future decisions regarding the service's provision of optimal levels of care.

BENIGN UPPER GASTROINTESTINAL DISEASE

The prevalence of peptic ulcers has fallen but the incidence of gastro-oesophageal reflux disease (GORD) has risen steadily over the last 10-20 years such that 20-40% of the population are estimated to have the condition. Dyspepsia accounts for between 1.2 and 4% of all consultations in primary care and, with IBS, accounts for the large majority of GI outpatient workload. In addition, approximately 7% of all infants will have GP input for reflux-related symptoms.

Helicobacter pylori infection is declining in the UK such that only 10-20% of 20-30 year olds are affected. However, the burden of related disease is still high with one in 35 men and one in 60 women in England and Wales estimated to die from a Helicobacter pylori related disease (primarily peptic ulceration and gastric cancer).

The economic impact of dyspepsia in primary care has been estimated at £11.25 per person per year totalling £500 million each year in the UK. Drugs for dyspepsia represent 10% of the total drug expenditure.

The service provision for benign upper GI disease relates closely to the provision of endoscopy services (see below). Apart from the management of upper GI haemorrhage, there is a relative lack of evidence to support any one model of service delivery for patients with dyspepsia or other upper GI symptoms but a consensus view would support the following recommendations:

Coeliac Disease

1. Management should be kept close to the patient and, in particular, a majority of patients with dyspepsia should be managed in primary care.
2. Endoscopy for patients with dyspepsia should be practised according to guidelines targeting those requiring exclusion of more significant disease (for example, age-related criteria, duration of symptoms, failure of empirical therapy). Test and treat strategies for *Helicobacter pylori* are cost effective in younger individuals and should be incorporated into dyspepsia guidelines.
3. Diagnostic endoscopy for dyspepsia may be delivered in primary care by GP specialists, except for endoscopy in children in whom paediatric anaesthetists are required, but the training and governance related to this should remain within the realms of secondary care.

With the increasing burden of GORD and the related rise in oesophageal adenocarcinoma, future strategies for managing upper GI disease need to encompass earlier detection of individuals at risk of developing Barrett's oesophagus.

Coeliac disease has a true prevalence of 1% of the UK population with much of this unidentified. This prevalence is the second highest in Europe. As a lifelong condition, patient self management is important in conjunction with primary care and with secondary care for initial diagnosis and treatment. Access to dietetic support is imperative and clinics specialising in Coeliac disease should have this as an integral part of the service. Bone density measurement is recommended in all patients.

As for other chronic disease areas, involvement of patient support groups is critical to successful management.

FUNCTIONAL GASTROINTESTINAL DISORDERS

Functional GI disorders (FGID) are defined by symptoms in the absence of structural abnormalities and affect all areas of the GI tract, ranging from globus (feeling of a 'lump in the throat'), non-cardiac chest pain (NCCP) and functional dyspepsia (FD) in the upper GI tract to irritable bowel syndrome (IBS) in the lower GI tract.

In addition to FGID, gastroenterologists treat a variety of complex GI motility disorders such as achalasia, gastroparesis, intestinal pseudo-obstruction and faecal incontinence. Some of these are rare and expertise in management may not exist at local hospital level.

Burden of Disease

Incidence

Dyspepsia (any symptoms alerting doctors to consider diseases of the upper GI tract) affects 20-40% of the population, accounting for 1-4% of all general practice consultations: half of these are for FD. NCCP may be of GI origin but sufferers often persist in the belief they have heart disease resulting in severe morbidity.

IBS affects 10-22% of the UK population. Its incidence appears to be rising, and it is about twice as common in women as in men. Only 50% of patients consult their GP and of these 1 in 5 are referred to hospital. IBS constitutes 20-50% of the outpatient gastroenterology workload.

Other conditions, such as achalasia and pseudo-obstruction are rare. Faecal incontinence, a major cause of social and psychological disability, is reported to occur in 2% of the adult population. It is particularly prevalent in the elderly and children and is a relatively neglected problem.

Requirements for Optimal Service

Morbidity and Costs to Society

The mortality rates for FGID are similar to the general population. However, these disorders have a significant impact on quality of life, both social functioning and work, with sufferers taking time off work and finishing their working lives at an earlier age. Over 40% report avoidance of activities including work, travel, domestic and leisure pursuits. 75% of NCCP patients suffer persistent symptoms and a poor quality of life over periods of 10 years or more: 30-50% never return to work and are unable to carry out household tasks. For all FGID a positive early diagnosis of a functional disorder can often be made, perhaps with a few well chosen investigations, by appropriately trained practitioners to reinforce the absence of serious disease which is often a concern to patients leading to anxiety, frequent consultation and persistence of symptoms.

1. To provide a high quality service to patients with FGID, the healthcare workforce must have the skills to meet the needs of the patients.
2. There is inadequate training of doctors in primary and secondary care to deal with patients with unexplained GI symptoms and complex motility problems. For trainees in gastroenterology, there is currently no requirement to obtain expertise in any GI physiological measurement techniques.
3. Most gastroenterologists rely on the expertise of GI physiology measurement technicians in interpreting the results of these investigations. Data held by the Association of GI Physiologists (AGIP) indicates that at present there are 0.77 GI physiologists per 100,000 population. Many units have only 1 or 2 personnel, making continuity of service provision problematic. Other professionals also undertake these tests (including clinical scientists, nurses and doctors).
4. With variations in experience, training and expertise of the technical staff there will invariably be variation in performance and interpretation of GI physiological measurement techniques. Additionally, some procedures are routinely used yet their efficacy is not clearly established (eg biofeedback therapy).
5. Specialist nurses, dietitians, pain management consultants and psychologists are valuable resources in secondary care for management of FGID and complex motility disorders. At both primary and secondary care level an integrated multidisciplinary service is often not available.

Recommendations

1. Development of neurogastroenterology as a subspecialty.
2. Ensure education of doctors in understanding and management of FGID at both undergraduate and postgraduate level. Training should include special modules in neurogastroenterology (the basic science underpinning understanding of FGIDs).
3. Ensure adequately staffed and trained GI physiology technicians in departments on at least a regional basis.
4. National audit of GI physiology departments, establish standards and ensure evidence-based practice. Encourage training in basic GI physiological measurement techniques.
5. More research into value of multidisciplinary approach to FGID in primary and secondary care.

Models of Care

1. The primary – secondary care interface: the vast majority of patients with FGID are managed in primary care. A smaller number are referred to secondary and tertiary care.
2. Self management at home: As in other specialties (including Inflammatory Bowel Disease in gastroenterology), there is emerging evidence that self-management of patients with FGID has distinct advantages.

Recommendations

1. Integrated service provision at the level of primary care with emphasis on a multidisciplinary approach to management of patients with FGID. Referral to secondary/tertiary care might be for clarification of diagnosis and formulation of a management plan or for management of rare complex disorders.
2. Need to research and develop effective self-management policies across the whole spectrum of patients with FGID.

INFLAMMATORY BOWEL DISEASE

Inflammatory bowel disease (IBD) is a paradigm for chronic disease. It commonly causes significant impairment of quality of life and this, together with the variation in the pattern and complexity of the symptoms that may affect patients at different stages of the illness, requires experienced and individualised clinical management with close and continuing collaboration between the patient and the professional team. IBD usually affects young people (median age at diagnosis 29.5yr) of working age and has a relapsing course that impacts on educational, social, professional and family life. The average cost of care is estimated at £3000 per patient per year. The UK prevalence is 240,000, so the cost of care for IBD in the UK can be estimated at £720m. Given the rapid therapeutic advances, this cost is likely to rise, although new biological therapy for Crohn's disease has been shown to reduce hospital in patient care in the UK. It is, with alcoholic liver disease and GI cancer, one of the three most important disease areas for UK Gastroenterologists. IBD is the topic of the first National Audit in Gastroenterology (2006-2009), with the BSG working in conjunction with the Royal College of Physicians, Association of Coloproctology and National Association for Colitis and Crohn's disease.

Patient Management

- Patient-centred care for IBD needs different approaches at different times within the life-long disease. No single model is appropriate for all patients all the time, although assisted self-managed care has been subject to one of very few randomised-controlled trials in this area.
- Choice between three approaches are appropriate: hospital care, shared-care with primary care and assisted self-managed care.
- Responsive health care means that any one patient will migrate between models of care according to the activity of disease, local facilities and personal preference.
- The necessity for choice in models of care is expensive since choice implies the capacity of individual models of care to accommodate extra patients. Each model of care needs an administrative and clinical infrastructure to support the process. Self-managed care should not become a euphemism for badly-managed care.

Primary/Secondary/Tertiary interface

- Patients contributed to National IBD Guidelines and want rapid access to a gastroenterologist who specialises in IBD, continuity of care and early referral of complex cases to specialist centres when local expertise is exceeded.
- Close liaison between primary and secondary care is facilitated by General Practitioners with a Special Interest (GPwSIs) if these independent practitioners have formal links (such as joint meetings, endoscopy session, or parallel clinics) with secondary care.
- Within secondary care, parallel clinics between medical gastroenterology, dietetics and colorectal surgery that focus care on patients with IBD should be the norm.
- An IBD multi-disciplinary team meeting should have similar priority to the cancer MDT but should take place separately.

- Long-term follow up of patients with extensive ulcerative colitis, or patients on immunomodulators, or patients with Crohn's disease is appropriate. Cancer complicating IBD is commonest in these patients. This means that customary measures of 'clinic efficiency' (such as New: Follow up ratios) are inappropriate and other measures, such as the percentage of such patients remaining under follow up, should be substituted.
- Ready access to other disciplines is necessary for the extra-intestinal manifestations of IBD, including rheumatology, dermatology, ophthalmology and oral medicine.
- Tertiary provision for an adolescent transition clinic should be established, to facilitate management of adolescent IBD and transfer of patients from paediatric to adult gastroenterology services at the age of 15-17yr.

Nursing and Allied Professionals

- The primary role of IBD Specialist Nurses (SpN) is to offer quality and depth to an IBD service.
- The activities of SpNs vary according to the needs of the hospital and community. These activities include providing telephone advice and support, facilitating rapid access to clinic appointments, coordinating patient-centred care, patient education, monitoring of immunomodulator therapy, bone-density and cancer surveillance programmes, training of ward staff and ward care, data-base management and research support.
- Working across professional and organisational boundaries is a key characteristic of specialist nursing. The IBD SpN is therefore ideally placed to co ordinate patient care as they move from one to another of the models described above.
- Dietitians with specialist knowledge of IBD should be an integral part of every IBD multidisciplinary team and should run clinics alongside the IBD clinic.
- Every patient with IBD should have an opportunity to see a dietitian.
- Areas that are under-provided, but important to IBD multi-disciplinary teams include clinical psychology or liaison psychiatry, smoking-cessation support for Crohn's disease, and medical social-workers or counsellors with expertise in the variable disability provoked by IBD. Such specialist members of a multi-disciplinary team should work across hospitals and in the community.

Training

- The cost, together with the complexity of biological therapy, is likely to see IBD emerge as a distinct sub-specialty.
- IBD is well placed to develop modular training in clinical science, as well as clinical networks that train specialists, provide access and monitor standards of practice in the use of complex biotherapy.
- The programmes should encourage access at regional, national or European levels with the support of Postgraduate Deans and training bodies.

Research

- CORE (DDF) and the National Association for Colitis and Crohn's disease (NACC) are the two principal sources of funding for research fellowships in IBD.
- An IBD Clinical trials network has been supported by the BSG and links with the American Gastroenterology Association established through an annual AGA-BSG research meeting.
- IBD should be a priority for research funding because in spite of novel therapy that developed from research into mechanisms of inflammation, it remains a chronic disease of unknown cause.

An Increasing Burden of Liver Disease

DIVERTICULAR DISEASE

Diverticular disease is an underestimated cause of significant morbidity and mortality. Complications of the condition are a major cause of death (1826 deaths per year (2000)). The incidence is rising and the condition has a prevalence of 5% at 40 years and 50% at 80 years.

Cases of difficult diverticular disease should be managed between primary care and a colorectal surgeon with experience in the condition. Early surgery may prevent complications.

ANO RECTAL SEPSIS

Ano rectal sepsis and its consequence of fistula formation is relatively common and presents a considerable management problem in the community. At present, there is no hard data to quantify this.

Treatment is often inadequate and prolonged. Centralisation of overall management of these patients with the employment of nurse specialists to track progress and supervise treatment may be the way forward.

LIVER & PANCREATIC DISEASE

The following are edited extracts taken from the National Plan for Liver Services published by the British Association for Study of the Liver in May 2004 and are in accordance with the overall strategy of the BSG as outlined in this document. For both liver and pancreatic disease it is envisaged that patients will be managed within a system of clinical networks. Although networks will largely coincide, in some cases the referral centres for complex hepatology and hepato-pancreato-biliary disease will be differently localized. Optimal management of patients with liver and pancreatic disease involves multidisciplinary team work with close cooperation of gastroenterologists, surgeons, interventional radiologists, nurse specialists, pathologists, intensivists and geneticists.

- Liver disease is an important cause of mortality in the U.K. In 2000 it killed more men than Parkinson's disease and more women than cancer of the cervix.
- The death-rate from alcoholic liver disease has doubled in the last 10 years.
- One in 25 people (4%) has abnormal liver function tests.
Of these 4% of the general population, ~0.7% will have chronic hepatitis C (HCV), 1% will have alcohol-related abnormal liver function, and 2% will have non-alcoholic fatty liver or other liver diseases.
- The government has recognized that management of hepatitis C to prevent the development of cirrhosis or liver cancer is desirable and cost-effective. Because of the increasing incidence of HCV, it is estimated that the future burden of HCV healthcare related to new incidence of cirrhosis will increase by 60% by 2008. There will be a 500% increased need for liver transplantation within the next 6-10 years, and a similar escalation in the incidence of liver cancer will be observed.
- The government has recognized that the rapid increase in the incidence of alcoholic liver disease is a major cause for concern.
- The improved diagnosis and management of infants with liver disease has increased survival leading to a need for transition services in adult units.

Acute Pancreatitis

- Incidence 20 per 100,000 population increase of 43% in the last decade mainly due to increased alcoholic pancreatitis and increase in gallstone pancreatitis secondary to dietary factors.
- 850 deaths per year (1.6 per 100,000 population)
- Facilities for early transfer to specialist centres for management of complicated acute pancreatitis are inadequate.

Chronic Pancreatitis

- Prevalence 40 - 75 per 100,000
- Incidence 8 per 100,000 and increasing

Hepato-Pancreato-Biliary Surgery (HPB)

- The liver is the commonest site for secondary cancer; 50% of the 30,000 people diagnosed with colorectal cancer will develop liver metastases, one-fifth of whom may be suitable for hepatic resection.
- The incidence of primary liver cancer is increasing. Thus, the incidence of hepatocellular carcinoma has doubled over the last 10 years, and is still rising. Similarly the incidence of cholangiocarcinoma has increased 10-fold over the same period.
- Pancreatic cancer affects 6-7000 people annually. 20% of these are suitable for a curative resection and many require palliative surgery. In addition, 2000 people per year are affected by non-pancreatic neoplasia of the duodenum, ampulla or bile duct and 40-50% of these are suitable for a curative resection.
- HPB surgery also has a major role in patients with benign conditions such as bile duct injuries, biliary strictures, pancreatitis and liver trauma.

Hepatology Services

There are 3 categories of hospitals that provide Hepatology services.

- District general and university-associated hospitals that have a gastroenterologist with a primary interest in liver disease.
- Teaching hospitals with a major interest in liver disease that does not undertake liver transplantation.
- Liver transplant centres.

There are 10-15 hospitals in the UK (including the 7 liver transplant centres) which would qualify as a Hepatology centre as defined later. It is not possible or desirable to concentrate all hepatology services in these centres. This applies particularly to the treatment of Hepatitis C. Whereas the management of complex liver disease is an inpatient process, often requiring highly skilled and high intensity work, the treatment of Hepatitis C is largely an outpatient process. However Hepatitis C treatment requires careful management because of the costs and complications of treatment. Ideally all doctors who deliver treatment for liver disease should be part of a defined clinical network, lead by a Liver Centre, which collects auditable data on outcome, efficacy and complications.

HPB surgery requires a high level of multi-disciplinary and surgical expertise to optimise outcomes. Operative procedures for HPB malignancy carry a high operative mortality which is related to both surgeon and centre volume. At least three or four surgeons should be working together in a team.

HPB Services

There are four groups of hospitals providing services for disease.

- All hospitals including district general and university-associated hospitals treat common conditions such as gallstone disease, uncomplicated acute pancreatitis, and are involved in the initial assessment of patients with HPB disease.
- A few hospitals have more expertise and undertake some HPB surgery in addition to the above but are not specialised pancreatic centres and may not be associated with a Hepatology Centre.
- Teaching hospitals with a major interest in HPB disease, but who do not undertake liver transplantation (approximately 8-10 such units). Each of the units will be a designated HPB or Pancreatic Centre.
- The 7 teaching hospitals who also undertake liver transplantation in addition to the above.

Hepatic, biliary and pancreatic surgery service provision requires a level of expertise that is not available at all hospitals. Many of the diseases involved, especially those with cancer, are associated with a poor long term prognosis, therefore it is important that patients receive optimal care by appropriately skilled staff. There is currently an inequality of service provision of HPB surgical services in the UK. The centralisation of services has not been matched by the required appointment of consultant surgeons and support staff in HPB Centres and Pancreatic Centres resulting in delay in treatment for this group of patients. With the new era of clinical governance and quality control, both the standard and the equality of access need to be improved.

Organisation of Liver Services in the Future

In the future we envisage that there will be a group (10-15) of managed clinical networks providing liver services across the U.K. Where appropriate each network will develop or embrace existing clinical care pathways for the management of a variety of Liver and HPB diseases. Where no guidelines exist, the profession will undertake to develop a concise set of treatment pathways to encompass the existing practice of UK hepatologists or HPB surgeons, so that data on clinical effectiveness can be compared. A key part of the National Plan for Liver Services is the development of accurate data collection as part of managed clinical networks on all major diseases or complications, so that clinical effectiveness can be compared between large groups of patients. Since clinical outcomes can be compared between large populations (1-5 million), the validity and strength of such comparisons will be scientifically stringent.

Liver and HPB Research Networks

Once the systems are in place to accurately collect auditable data on treatment and outcomes, there should be an initial assessment of clinical effectiveness of the various treatment options available for the management of patients. This may take place through planned research or simply through audit of current clinical practice. Therefore Research Networks need to be developed served by a team of research nurse practitioners, who will facilitate such research programmes

Nurse Specialists

A number of specialist nurses will be required to deliver anti-viral therapy and to coordinate the care of patients. For viral hepatitis, each specialist nurse should be able to manage 50 patients undergoing therapy for viral hepatitis at one time. A variable number of specialist nurses (currently severely under resourced) will be required to care for patients with HPB cancer, depending on the size of the managed clinical network, in order to facilitate communication and provide psychological support and social, spiritual and palliative care. Each pancreatic centre providing services for pancreatitis should have at least one specialist pancreatitis nurse liaising with in patients and out patients and providing a full range of support services for clinicians in outlying hospitals.

Requirements for each Hepatology Centre

Each Hepatology Centre should be able to provide the following services:

- Advice for district general hospitals on the management of complex liver disease.
- Admission, diagnosis and management of rare or complex liver diseases.
- Admission, diagnosis and management of hepatocellular carcinoma & cholangio-carcinoma.
- Basic work-up and advice for patients who may need a liver transplant.
- Admission and management of patients with recurrent variceal haemorrhage.
- The placement of a transjugular intra-hepatic portosystemic shunt (TIPSS) if indicated for variceal haemorrhage, diuretic resistant ascites or hepatic hydrothorax.
- Renal support if indicated for patients with the hepatorenal syndrome.
- Advice and support to patients through a liver support group and/or clinical nurse specialist.
- Advice and support for patients with substance misuse problems.
- Link with one of the Paediatric Liver Units for the management of children and adolescents.

Requirements for each HPB or Pancreatic Centre

Some pancreatic centres may not be providing the full range of services for hepatic surgery and therefore will be pancreatic centres rather than HPB centres. Each HPB Centre should be able to provide the following services:

- Each centre should serve a population of 2 to 4 million, and be capable of the diagnosis, assessment & management of benign and malignant HPB disease and trauma.
- Full diagnostic and imaging facilities including interventional radiology, endoscopic ultrasound and state of the art axial imaging.
- Ability to interact, daily if necessary, with referring hospitals. Teleconferencing of MDT meetings for malignant and benign disease.
- Ability to provide capacity for emergency in patient transfer.
- Management of biliary disease will include complicated gallstone disease, biliary tract cancers, bile duct repair and bile duct resections. Provision of complex pancreato-biliary and endoscopy procedures.
- Management of patients with pancreatic disease including pancreatic resection for benign and malignant disease. Management of severe pancreatitis and management of complicated chronic pancreatitis.
- Management of hepatic disease including primary and secondary liver cancer. Hepatic resection. Ablation of liver tumours and palliative surgery for HPB cancers. Management of complicated benign inflammatory/neoplastic HPB disease. Portal hypertension surgery.
- Management of HPB trauma including blunt and penetrating trauma and complications of endoscopic and surgical procedures.

ALCOHOL RELATED GASTROENTEROLOGICAL PROBLEMS

The care of patients with alcohol-related diseases causes particular difficulties to gastroenterologists. The liver and GI tract are the most common focus for alcohol-related damage and in most inner-city hospitals, the management of in-patients with alcoholic liver disease and its complications is the largest single workload that GI physicians face. Furthermore, when around 20% of unselected emergency admissions are alcohol related, many of them gravitate to GI physicians under triage systems even when there are no specific liver or GI problems, for instance patients suffering from alcohol withdrawal or the social consequences of alcohol dependence.

It is important to anticipate that the burden from alcohol, not only alcoholic liver disease but also alcohol pancreatitis is going to increase markedly over the coming decade or more. As a nation, we are drinking more than for 90 years and there is a lag time between consumption and cirrhosis. Already, we have seen a 350% increase in cirrhosis between 1970 and 1998, and this figure is 900% for those under 45 years of age. Patients with alcoholic cirrhosis and alcoholic pancreatitis and related complications are heavy users of expensive hospital resources, particularly length of stay, intensive care, blood and interventional procedures, and they are often regarded by other specialties and departments as of lower priority because of the perceived self-afflicted nature of the condition.

GI physicians accept their key role in the management of patients with alcohol-related disease but realise that they cannot take on this load without explicit consideration of the implications. Fortunately, there is an evidence-based blueprint for managing alcohol-related diseases produced in 2001 and reaffirmed at a recent joint Royal College of Physicians/British Society of Gastroenterology conference in early 2005 entitled "Alcohol-related harm – a growing crisis, time for action!"

There were recommendations about national policy, research and education, but the key recommendations (summarised below), were for local care by acute hospitals receiving unselected medical admissions:

1. Screening strategy for early detection of harmful/coincidental hazardous drinkers.
2. Early assessment of dependence severity by appropriately trained staff.
3. Widely available protocols for the pharmacotherapy of detoxification.
4. Readily available "acute response" from liaison or specialised alcohol psychiatry services for the management of patients undergoing "complicated" alcohol withdrawal.
5. Assessment of the need for referral to on-going support services by appropriately trained staff with knowledge of local services.
6. Provision of brief interventions for coincidental hazardous drinkers.
7. Provision of general staff education.
8. Occupational policies for alcohol for all hospital health care workers, for examples with respect to drinking at work.
9. Close liaison with General Practitioners on discharge.

Trust's strategy should include the identification of:

1. A senior member of medical staff and a senior member of nursing staff to act as a focus for alcohol strategy and to support more junior members of staff.
2. Senior psychiatric colleagues with an interest in the management of alcohol problems to act as the primary link between the acute hospital trust and local mental health services. This individual may or may not be employed by the acute trust.
3. One or more dedicated alcohol health workers employed by and answerable to the acute Trust. The roles will include:
 - a. Implementation of screening strategies.
 - b. Detoxification of dependent drinkers
 - c. Brief interventions in hazardous drinkers.
 - d. Referral of patients for on-going support / with access/knowledge about locally available non-statutory / voluntary agencies.
 - e. To provide links with liaison/specialist alcohol psychiatry.
 - f. An education resource and support focus for other health care workers in the Trust.

Responsibility for the development of the alcohol strategy and its implementation should be undertaken by a steering group consisting of these clinical staff together with senior managerial personnel from the Acute Trust and Mental Health Trust and Representatives from local primary care services, public health and purchasers.

After identification of a lead clinician (usually a Gastroenterologist or Hepatologist, but it may be a consultant in A+E in some hospitals where they have an interest), the key appointment is that of an alcohol specialist worker. There is published evidence of their efficacy, and in hospitals where appointments have been made there have been reductions in admissions and length of stay and improved safety from, for example, implementation of detoxification regimes. However, take-up by acute hospitals has been slow, rising from 4% in 2000 to 13% in 2003 of hospitals surveyed. Managing the health consequences of the rising tide of alcohol misuse in the United Kingdom will be one of the key challenges of the future, and much of it will fall to the gastroenterology and Hepatology services in acute hospitals.

OBESITY

Obesity is well recognised as a major healthcare issue in the western world with a current prevalence of 20% in the UK (defined by Body Mass Index greater than 30kg/m²). The impact on delivery of GI services related particularly to the high prevalence of fatty liver disease (see burden of liver disease above), gastro-oesophageal reflux disease and to the increasing demand of bariatric surgical services, especially for those with morbid obesity, is considerable and likely to increase.

NUTRITION

Absorption of nutrients and water is the principal function of the GI tract. Dealing with failure of the gut to subserve this purpose clearly falls within the remit of the Gastroenterologist. Nutritional support should be seen as an automatic part of the holistic care of any patient with GI disease and indeed those with non-GI disease as described in the RCP publication, "Nutrition – a doctor's responsibility".

Under nutrition is prevalent in the community and UK hospitals and often worsens during a hospital stay.

- Nutritional support in hospital is best provided by a multidisciplinary team comprising doctors, specialist nurses, dietitians and pharmacists. Gastroenterologists should be central to the function of such a team.
- Training of gastroenterologists should include accreditation in nutritional support. Increased training and funding of specialist nurses, dietitians and pharmacists is essential to improving optimal service delivery.
- All acute hospitals should have a Nutritional Support team.
- Expertise for placement of Percutaneous Endoscopic Gastroscopy (PEG), Percutaneous Endoscopic Gastro-Jejunostomy (PEG-J), Percutaneous Endoscopic Jejunostomy (PEJ) and fine-bore jejunostomy tubes should be available in every DGH and tertiary centre.
- Links to the community for ongoing nutritional care are essential as are links with stroke services and other neurological services.

Recommendations regarding service delivery

Keeping Care Close to the Patient

- Likewise, specific facilities for placement of central feeding catheters should be available through experienced individuals such as anaesthetists, intensivists, radiologists, surgeons, gastroenterologists or specialised nurses.
- Home parenteral nutrition services need to be increased to meet the burden of disease in the UK. To date, no centres have been commissioned to provide HPN services and only two national centres exist for treatment of complex intestinal failure.

SERVICE ISSUES

Over riding principle: “delivery of care must be patient-centred”

Assisted self-management of patients is playing an increasingly important part in patient care. There is good evidence that patients with chronic diseases such as inflammatory bowel disease or irritable bowel syndrome can manage themselves with fewer hospital or General Practitioner appointments if they are given enough education about their condition, including how to cope with the physical, emotional and social implications, and are supported by expert services that they can easily access. This approach could be extended to a wide variety of chronic diseases which would potentially reduce demand on conventional services.

High quality gastrointestinal services should be delivered locally wherever possible. There should be closer integration between primary and secondary care with the development of care pathways and models of care for chronic diseases.

Clinical Governance should be strictly applied to the Primary/Secondary Care interface.

Primary Care Trusts should review the delivery of GI services and ensure that consultations and diagnostic services are available locally.

Trusts and their clinical teams should review GI services and consider whether any service could be shared locally eg ERCP, Motility/Manometry studies, Endoscopic Ultrasound (EUS).

Location of Services

Centralisation of some services is essential, eg complex liver disease, liver transplantation, complex hepato-biliary and pancreatic disease and home TPN. However, the move to centralise services, especially cancer, based on population size will also centralise surgical, radiological and pathological services and has the potential to impair the available services in the District General Hospitals where most of the care still has to be provided. The Swansea Review Document has found no evidence to support the benefit of such a re-allocation. The loss of surgical expertise, to manage cancer centrally, would deprive District Hospitals of the necessary surgical skills to manage non-cancer surgery. It would also have a detrimental effect on training opportunities. It is crucial that the required levels of skill and expertise are maintained at a secondary level to provide the optimal care required in management of emergency gut, liver and pancreatic problems.

Evaluation of the Service/Quality Control

An overwhelming finding of the Swansea Review is the paucity of good research or evaluation relating to initiatives in service delivery. A fundamental recommendation must be that this is introduced.

There is urgent need for better IT support for clinical care in Gastroenterology. Without such support, introduction of comprehensive quality control would not be possible. The workforce and facilities must be funded to provide this service data.

The need for National Audits of clinical practice is recognised yet their funding is beyond the capacity of Specialist Societies and should be met by central Government.

Workforce

Delivery of optimal gastrointestinal services requires a co-ordinated approach involving primary and secondary care teams. The essential members of the secondary care team are surgeons, physicians, radiologists and pathologists with their supporting medical teams. These teams need to be supported by specialist nurses covering the areas of stoma care, nutrition, cancer, palliative care, endoscopy and general gastroenterology.

A close working relationship with allied specialties such as dermatology, haematology, rheumatology, genetics and psychiatry is essential for the complete service. Any increase in clinical demand will impact on all these groups and requires appropriate increased provision.

The Royal College of Physicians' (RCP) document "Consultants Working with Patients" (2005), has suggested the need for 1 Consultant Gastroenterologist per 40,000 population. The Burden of Disease, the rising incidence of gastrointestinal diseases, and the Drivers for Change indicated above, confirm the justification for the recommendations in the RCP report for this increase in Consultant Gastroenterologists. It follows that corresponding increases in manpower in other disciplines allied to gastroenterology will be necessary to provide this service. At the time of writing, detailed manpower data is not available for surgery, nursing or primary care.

Manpower issues in the surgical disciplines are complex and less easy to define. The implementation of COG Guidelines, particularly in relation to upper GI surgery, has certainly impacted on upper GI trainees in the short term. There is nevertheless an increasing burden of benign work in upper GI practice. The Association of Upper GI Surgeons (AUGIS) recognises that small district general hospitals will have laparoscopic upper GI surgery available and these surgeons will have been trained in emergency upper GI surgery and may well provide a laparoscopic service for both reflux disease and obesity. It is, however, recognised that the number of Units necessary to provide upper GI resectional surgery will decrease over the next few years. AUGIS nevertheless anticipates that the number of surgeons providing that service will remain largely unchanged. This is because of providing 24 hour, 7 days a week upper GI cover in such institutions and rationalisation of programmed activities within the new contract. An ongoing audit is at present designed to produce more specific figures.

There is strong evidence that surgeons with sub-specialty training demonstrate better outcomes compared with surgeons who have no such training. The concentration of colon and rectal cancer surgery and increasing sub-specialisation have coincidentally resulted in a similar concentration of inflammatory bowel disease surgery, fistula surgery and the management of functional lower GI problems referred to specialist colorectal surgeons. Changes now happening in surgical training are likely to increase specialisation within general surgery even further, to the extent that it is likely that almost all elective colon and rectal surgery in the future will be done only by surgeons who have had specialist training in coloproctology.

Colorectal surgeons bare the brunt of the emergency take with 70% of emergency cases being colorectal. Taken together with the increasing demand for colonoscopy, their

Chronic Disease Management (CDM)

numbers need to be increased substantially, perhaps doubled. However, this to a large extent depends on the ultimate configuration of services.

A major part of the substantial and increasing workload in gastroenterology relates to those patients with chronic disease. Inflammatory bowel disease and chronic liver disease are examples. Re-designing and developing CDM is essential to provide patients with better care. The principles are to take care close to the patient and, where appropriate, to develop assisted self-care involving patients in their own care.

Devolving more care to primary care level and the development of GP's with specialist interests leading to closer integration of care between primary and secondary care levels is essential. This can be achieved by education, training, the development of agreed patient pathways and the development and agreement on patient protocols of care. Multi disciplinary team working is fundamental to the success of chronic disease management with a greater overlap of specialist nursing support between primary and secondary care, with the use of telephone help lines and improvement and easing of access to secondary care.

More effective CDM should reduce the need for in-patient care and reduce demands of specialist out patient clinics, helping to achieve national waiting list targets and providing care in the least intensive setting.

However, it cannot be achieved without appropriate resources to fund the education, training and workforce requirements and must be underpinned by good information systems and on going support such as telephone help lines.

Endoscopy Services

Burden

There has been a progressive and sustained increase in both the demand for, and numbers of, endoscopies performed. Currently about 1.4–1.6% of the population undergo upper gastrointestinal endoscopy per annum, while about 0.8 % undergo flexible sigmoidoscopy and 0.6% colonoscopy. ERCP and EUS is undertaken on 0.2% on average.

It has been estimated that with the introduction of colon cancer screening and compliance with NICE guidelines there should be a change in the proportion of endoscopies so that upper endoscopy should decrease to 0.8%, while both flexible sigmoidoscopy and colonoscopy should increase to 1% each, with little change in the proportion of ERCP and EUS.

Until recently many units had long waiting lists for routine diagnostic endoscopies and in some even urgent endoscopies might take many weeks before being performed.

Many different pathways exist into endoscopy units: direct access, 2 week rule, surveillance, screening and emergency. The complexity in delivering an efficient service is related to the type of patient, priority of need, type of endoscopy required and the skill mix of staff available to deal with the workload, as well as structural facilities and equipment availability.

Major changes have taken place in the last few years aimed at improving the service to patients

Drivers for Change

Considerable changes have occurred in the provision of endoscopic services from training to service provision and quality assurance.

Training

The adoption of the JAG recommendations for training in endoscopy have for the first time provided a means of assuring that whoever undertakes endoscopy should be trained to a common approved standard, irrespective of their educational or training background. In addition, it is recognised that endoscopy in children should, wherever possible, be performed by paediatric gastroenterologists.

Additionally the move from completion of training from numbers performed to detailed assessment of competence is thought to provide a better method of assessing the quality of an endoscopist.

The provision of £10.6M over a 6 year period by the National Cancer Plan has led to the provision of JAG approved courses from designated Training Centres in England, although not as yet in other countries of the UK. Formally trained trainers are thought to be an essential component of the provision of high quality skills training.

Attendance at such courses has become a mandatory part of training.

Proof of better outcomes from the National Training Programme is awaited.

All such training has to be compliant with the Competency Framework for staff in the Health service.

Service Delivery

With the development of the Endoscopy Project of the Modernisation Agency considerable improvement in efficiency of units has been shown to be possible by use of the 'Toolkit'. Accurate definition of capacity and demand of a service, together with a set of methods to improve the through put, has enabled many units to reach, or get close to, the intended DoH aims of all urgent endoscopies being performed within 2 weeks and all routine procedures within 6 weeks. In many cases extra resources may be required, but adoption of the principles of the 'Toolkit' will reveal the true need, enabling the staff to go to management with strong evidence.

The SHA Endoscopy Leads are there to aid improvement of service.

Quality Assurance

Quality assessment of endoscopy is essential to ensure necessary high standards. This report supports the steps that are being taken in the development of the Global Rating Scale of patient experience, to develop a competency framework for endoscopy staff, to ensure appropriateness of endoscopy and to develop quality and safety markers. Most units now regularly submit their Global Rating Scale results twice a year to the Department of Health.

The necessary expansion of endoscopists will need increased training, dedicated training lists, certification and revalidation of endoscopists particularly for the colon screening programme and accreditation of endoscopy units. A Global Training Rating Scale is currently being piloted.

The increasing demand for endoscopy and the reduced availability of Consultant Gastroenterologists due to competing demands points to the need for changing roles in endoscopy.

Requirements for Optimal Service

- Compliance with Modernisation Agency service improvement programme, with capacity and demand assessment and process mapping.

Specialist Gastroenterology Nurses

- Communal waiting lists.
- Reduction in down-time of endoscopy rooms with backfilling of lists.
- Employment of non-medical, trained endoscopists to deliver basic diagnostic services.
- Use of Global Rating Scale to assess the quality of the service being offered.
- Full range of modern diagnostic endoscopy equipment with computerised recording of results, image capture and appropriate training facilities.
- Provision of JAG approved training for all endoscopists, by trainers who have completed JAG compliant Training the Trainers Courses.
- Appropriate training for all other endoscopy related staff using established competency frameworks, and in line with Agenda for Change.
- Planning for introduction of Bowel Cancer Screening.
- Compliance with all current BSG and other relevant National Guidelines.
- Delivery of requisite numbers of specifically and adequately trained paediatric endoscopists working within hospitals able to provide paediatric anaesthesia and paediatric GI histopathology.

Drivers for Change

There is increasing need for non-medical professional staff to help provide an efficient, timely and high quality service for patients with gastrointestinal disease.

Changes in junior medical staff training (Calman, European working time Directive, Modernisation of Medical Careers) has meant a reduction in patient contact time and continuity of care. In addition the modernisation of endoscopy services and reduction in waiting times has led to a need for other trained professionals to undertake some of their duties, within the scope of their professional role.

There has been an increase in nurse led clinics including monitoring functions for high risk patients (Barrett's, IBD, patients on immunosuppression) as well as managing patients in protocol based clinics (anaemia, dyspepsia, coeliac, IBS). Many of these clinics could be held outwith secondary care, linking primary and secondary care.

Nurse specialists are popular both with patients and doctors and their primary task is to offer quality and depth of service. Their roles are not clearly defined because these differ in different hospitals and communities. Their roles include providing telephone advice, facilitating rapid access to clinics, patient education, monitoring of drug therapy, providing some physiological testing and the carrying out of research, audit and the production of guidelines, to mention just some of their work. They are becoming an indispensable part of the team and their numbers are increasing. To provide these services, a minimum of two specialist nurses would be required within a gastroenterological team.

Endoscopy Related Nursing

The appointment of trained nurses to undertake much of routine basic endoscopy (diagnostic upper endoscopy and sigmoidoscopy) has been accepted widely throughout the UK. Estimates of their numbers vary from 2-300 at present. There is good evidence that nurses are safe and effective when undertaking diagnostic endoscopy and patient satisfaction is better than when the procedure is done by doctors. Their ability to reduce endoscopy unit down times has increased throughput by up to 30%. Increasingly nurse endoscopists are being involved in more advanced techniques such as colonoscopy and some aspects of therapeutic endoscopy (polypectomy, PEG placement). In addition their experience is being utilised in the training of other endoscopists, both medical and non-medical to JAG standards.

In some Units the appointment of Nurse Endoscopists from the ranks of Endoscopy Assistants has put pressure on the delivery of the service.

Radiographers are also increasingly being trained to undertake endoscopy, in order to provide a seamless service combining flexible sigmoidoscopy and barium enema as a one stop diagnostic facility.

The Dept of Health has funded a pilot scheme for training non medical, non nursing personnel such as medical laboratory technician, in the performance of flexible Sigmoidoscopy. The value to service delivery has to date not been established.

A few Nurse Consultants undertaking endoscopy are undertaking even more advanced therapy such as participating in GI bleeding rotas, banding of varices and oesophageal dilatation, and some provide EUS.

It is thought inadvisable for Nurse Endoscopists to work solely doing Endoscopy lists, or to work as Endoscopy assistants when they are not endoscoping. Other duties such as attendance at clinics, or running nurse led clinics as well as related Endoscopy sessions should be included in their job plans to enhance their job satisfaction and improve the service to patients.

Most endoscopy units are run by highly trained nurses acting as endoscopy assistants who are supported by health care workers, technicians and administrative and clerical staff. All groups require formal training in order to provide a high quality, safe service, currently being assessed by the Global Rating scale.

Specialist Nurses (Non Endoscopy)

In the last 10 years there has been a marked increase in the number of such nurses employed to assist in the delivery of high quality Gastrointestinal services.

There is a large range of specialisms of such nurses (IBD, Upper GI Cancer, Lower GI Cancer, Nutrition/PEG, Liver Disease, Genetics) however most are trained in-house by their Consultants and there are few courses or qualifications specifically available for their development.

There is a belief that their employment both improves the provision of service and adds considerably to the quality of the services offered to the patient, their families and carers. Patient organisations such as the National Association for Crohn's and Colitis (NACC) have so valued these nurses that they are supporting a campaign to increase the number employed in the UK. At present, both NACC and the Royal College of Nursing (RCN) estimate there are about 150 nurses with a significant specialist IBD role in the UK, though many have other roles as well.

Stoma Nurses now form an essential part of the medical /surgical gastroenterological team and a minimum of 2 would be required to provide continuity of service in an average DGH. There are approximately 400 in the UK at present, of whom 50% are company sponsored. These 50% may be under threat from changes to prescribing reimbursement, at present under consultation in England.

The colorectal cancer nurse network has 80 members who spend at least 50% of their time on colorectal cancer.

There are very few nurses (possibly a handful across the country) specialising in the management of pancreatitis. It is the belief of pancreatic specialists that a pancreatitis nurse should be attached to each pancreatic centre to provide a service for those patients with pancreatitis in addition to specialist pancreatic cancer nurses.

Over the last 5 years there have been increasing numbers of Nurse Consultants appointed, usually from the ranks of Specialist Nurses

Other GI Nurses

Most District general hospitals, as well as larger Teaching Centres, now have dedicated gastrointestinal wards, both medical and surgical, and the nursing staff on these wards need specific training. In some centres rotations between medical and surgical gastroenterology wards as well as the endoscopy unit are undertaken to provide a multi-skilled workforce. In some hospitals the wards are joint medical and surgical.

Similarly training for clinic staff is essential to provide a quality service to support the medical staff and specialist nurses.

Other Health Professionals that are essential to the provision of a comprehensive service include Dietitians, Pharmacists and other supportive therapists

Requirements for Optimal Service

- Trained nursing staff in each area looking after gastroenterology patients (clinics, wards, endoscopy units).
- Specialist Nurses in IBD, Stoma Care, Liver Disease and Nutrition as a minimum. Cancer Specialist Nurses are needed for Upper GI, Hepatobiliary/Pancreatic and Colorectal cancer, but whether these nurses are aligned with surgeons or physicians will depend upon the structure of the Multidisciplinary Team. In all but Upper GI Cancer most of their work is related to surgery, whereas in oesophageal and gastric cancer many patients do not undergo surgery and require different nursing skills.
- National standards and competencies for SpN in gastroenterology should be developed, supported by programmes of education and continuing professional development.
- Local networks of SpN nurses involved in gastroenterology should be established to avoid the impact of professional isolation.
- Most leaders in the field do not think that nurse endoscopists should undertake only Endoscopy, but should have some other responsibilities such as related clinic duties.
- There is uniform agreement that Nurse Endoscopists should not also work as Endoscopy Assistants.

Medical / Surgical Interface

ALLIED GROUPS

Perhaps more than in any other specialty, gastroenterology requires a close working relationship between surgeon and physician. The provision of best care for patients with gastrointestinal disorders must be through integration and cooperation between medical gastroenterologists and gastrointestinal surgeons, both upper and lower. The following are required to support this essential relationship.

Multidisciplinary Team Meetings (MDT's): These are required on a weekly basis, both for cancer and non-cancer disorders. The rapid development of cancer MDT's has occurred at the expense of non-cancer MDT's and this needs redressing.

Where possible, combined wards, ward rounds and out patient clinics, should be developed with shared responsibility for endoscopy services. HPB surgery and pancreato-biliary gastroenterology with advanced endoscopy benefit especially from a combined medical-surgical team approach. There are several examples nationally where this close working relationship is proving very successful.

The Royal College of Physicians report quantifies the increased requirements in terms of consultant medical gastroenterologists. This increase needs to be accompanied by a commensurate increase in surgical expertise, nursing and support services.

Pathology Interface

The BSG Pathology Section plays a key role in promoting the provision of a high-quality gastrointestinal pathology service across the UK. There are several key areas within gastrointestinal pathology that need developing to ensure that standards are maintained. Of most importance are:

- *Identification of the most appropriate way in which a gastrointestinal pathology service can be provided on a national basis by both 'general' pathologists and specialist gastrointestinal pathologists.* There is a growing move towards increasing specialisation within Cellular Pathology across the UK – this is most advanced within larger hospitals and is likely to continue as a trend with many smaller hospitals becoming amalgamated with large centres. However, the smallest hospitals and the most remote units are not likely to provide a fully specialist service if they retain Cellular Pathology on-site. Therefore, the concept of a 'general' pathologist is likely to persist in some areas for at least several years. There needs to be optimal interaction between pathologist working in a general setting and those working a specialist centre. This should include the development of guidelines for the referral of difficult or unusual cases and the formalisation of referral pathways.
- *Development and promotion of reporting guidelines for non-neoplastic gastrointestinal disease.* The Royal College of Pathologists (RCPATH) has already produced detailed 'minimum dataset' guidelines for the major cancer resections within gastrointestinal disease and these are widely used. However, few equivalent guidelines exist for benign disease. Therefore, clinical practice is varied for these specimen types. There is a need to develop guidelines in these areas and the Pathology Section is working with the BSG to produce these.
- *Maintenance of standards in gastro-intestinal pathology.* The BSG Pathology Section is the central focus for gastro-intestinal education and CPD in the UK. The Gastro-intestinal External Quality Assurance (GIEQA) scheme is administered and run through the Pathology Section and appropriate educational events take place under the umbrella of the BSG in concert with the Association of Clinical Pathologists.

- *Determination of the workload implications for pathology departments associated with new screening programmes – especially for colorectal cancer.* Consideration needs to be given to creating advanced practitioners in Cellular Pathology who might work in a similar way to cytoscreeners within the NHS Cervical Cancer Screening Programme. Such posts would need to be supported with a proper training and quality assessment programme.
- *Promotion of the value of academic gastrointestinal pathology.* Academic pathology has suffered in the same way as the rest of academic medicine in recent years. It is important for the future of gastrointestinal disease research that trainee pathologists expressing an interest in academic activity are encouraged and supported.
- *Exploration of the potential value of videoconferencing and telepathology for specialist referral work and for input into remote multidisciplinary team meetings within hospital networks.* This will become an increasing requirement with the amalgamation of small units and larger centres. Indeed, the current difficulty in recruiting consultants in Cellular Pathology has resulted in the collapse of pathology services in some units and the requirement for amalgamation with a larger centre.

Radiological Interface

Both diagnosis and management of patients with gastroenterological conditions depends heavily on radiological support. This has become even more apparent with the development of MDT's where joint discussions are crucial in patient management. Between 30 and 40% of work in radiology can be related to gastrointestinal patients.

This aspect of gastroenterological care is threatened by the gross under funding of radiology in the UK when compared internationally. There are not enough Radiologists in the UK to cover the demand, especially in interventional radiology. This will impact on the growth of GI services both diagnostic and interventional. This manpower issue is currently being addressed by the Royal College of Radiologists and the Department of Health. Furthermore, the move to outsource radiology and, in particular, MRI would tend to weaken the close working relationship between radiologists and their clinical colleagues that occurs in this country. This is a strength of the current service and arises out of the clinical background of radiologists in this country. Radiologists also act as important gatekeepers on the overuse of limited resources. The increase in the overall amount of radiology performed, particularly in the community, will result in the investigation of more and more incidental findings.

There are areas of growth in gastroenterological imaging that are high tech, requiring considerable resources and expertise. These include virtual colonoscopy (currently CT but may well involve MRI), MRI techniques for small bowel disease and complex MRI studies involving liver contrast agents in MRI. PET-CT scanning is currently an under resourced procedure nationally but could have a definite role for tumour staging in GI malignancy. Close liaison between the radiologist and clinician would be crucial in the success of the interpretation of these studies and their value in patient management.

More multidisciplinary research is needed into new techniques such as PET-CT, MR and tumour ablation. This not only requires multidisciplinary input but probably also a multicentre approach to obtain adequate numbers.

In the management of liver disease, there has been a shift from surgical to radiological interventional treatment for the management of complications of liver disease such as TIPSS procedures, treatment of cancer with embolisation and local regional techniques such as radio frequency ablation as well as the widespread need of imaging in liver disease. This is resulting in a sub-specialisation in hepato biliary radiology. This specialisation and need of liver expertise in the radiological field is necessary also in secondary centres. It is no longer possible to manage liver disease without specialist radiological support.

Clinical Physiologists in Gastroenterology

At present, there are 38 accredited units and 74 accredited practitioners in the whole of the United Kingdom. There is great variation in the workload in different departments, varying from 200 to 2500 patients per year. There is also a wide range of the upper and lower GI physiological measurements available at different centres. In many departments, there are only one or two practitioners, leaving individuals to work alone in isolated areas.

Physiological measurement in gastroenterology is essential for the management of many benign gastroenterological diseases. There is the capacity and the ability to train more physiologists without an impact on the existing service. At a recent workforce planning meeting with the chief scientific officer, it was concluded that the GI workforce in physiological measurement should at least be doubled to go anywhere near addressing the clinical governance issues and also to enable the 18 week wait target to be achieved.

Dietitians

It is hard to think of any area of gastroenterology where diet and the input from dietitians is not important. Dietary advice, for example, is essential in the management of patients with gastrointestinal cancer and inflammatory bowel disease and of great value in functional bowel disorders.

Dietitians should be essential members of any gastrointestinal team, their input being required across a spectrum of primary and secondary care, home visits, GP clinics, hospital out patients and the wards.

Greater dietary input would enable many patients to manage their conditions at home. There is an increasing opportunity for specialist clinics, for example in coeliac disease, and for disease prevention and health promotion. This is particularly relevant at a time when obesity and cancer levels are on the increase.

Another expanding area which depends on dietary supervision is the placement of gastrostomy tubes. It is estimated that between 22,000 and 27,000 people are now tube fed at home. These patients need support and monitoring in the community and tube placement. The increasing numbers of such patients impacts directly on gastrointestinal services.

An increase in dietitian numbers must parallel the necessary increase in gastroenterology and nurse practitioner staffing levels highlighted in this document. This needs dedicated budgets for service provision.

PAEDIATRIC GASTROENTEROLOGY

The British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN) which is represented in the BSG through the Paediatric Section of the BSG has developed standards for services in the following documents – Guide for Purchases of Paediatric Gastroenterology, Hepatology and Nutritional Services and Commissioning Tertiary and Specialist Services for Children and Young People (www.bspghan.org.uk).

A major driver for change was the production of the National Service Framework for Children, Young People and Maternity Services, a document which includes standards for adolescent transition (www.doh.gov.uk/nsf/children.hgn).

Liver Diseases

The improved diagnosis and management of infants with liver disease has increased survival leading to a need for transition services in adult units. Paediatric liver disease and transplantation is managed at three national centres (Birmingham, Leeds and Kings College London). Liver/intestinal transplantation in children is only provided in Birmingham Children's Hospital.

Links with one of the paediatric liver units for the management of children and adolescents should be available in each hepatology centre.

Inflammatory Bowel Disease

IBD is a core area for paediatric gastroenterologists, constituting a major part of their clinical activity. Children should be looked after in an appropriate "child friendly" setting and by paediatric gastroenterologists. By virtue of its relative rarity in the context of childhood disease, IBD is considered to require involvement of a tertiary service (specialised services definition set – [www.doh.gov.uk / specialisedservicesdefinitions/23childrewn.pdf](http://www.doh.gov.uk/specialisedservicesdefinitions/23childrewn.pdf)).

A substantial minority of patients with IBD first present in childhood and must be cared for in the early years of their illness within the paediatric specialist services. Most general paediatricians have little experience in the diagnosis and management of IBD. Crohn's disease has an incidence in children under age 16 of about 3 per 100,000 population in the United Kingdom. While most children with IBD have Crohn's disease, about 20-30% have ulcerative colitis. Misdiagnosis and delayed diagnosis is a significant concern in childhood IBD. Expert paediatric endoscopic and surgical services are essential. IBD in childhood is often associated with impaired growth and suboptimal management may substantially increase the risk of permanent stunting of growth.

All children with suspected IBD should be referred to a specialist paediatric gastroenterology unit. It has been recommended that specialist units should have a population referral base of sufficient size (approximately 2 million) to justify the appointment of three paediatric gastroenterologists and a multidisciplinary specialist team and to allow the maintenance of appropriate clinical and endoscopic expertise. The advent of new therapies and changing treatment algorithms make centralised care even more important. In order to be able to provide a high quality of care in every region, close collaboration with easy access to the diagnostic services at the 'hub' is essential. Experience of the newer therapeutic agents is likely to be limited to larger centres, with many being available only in the setting of multi-centre trials.

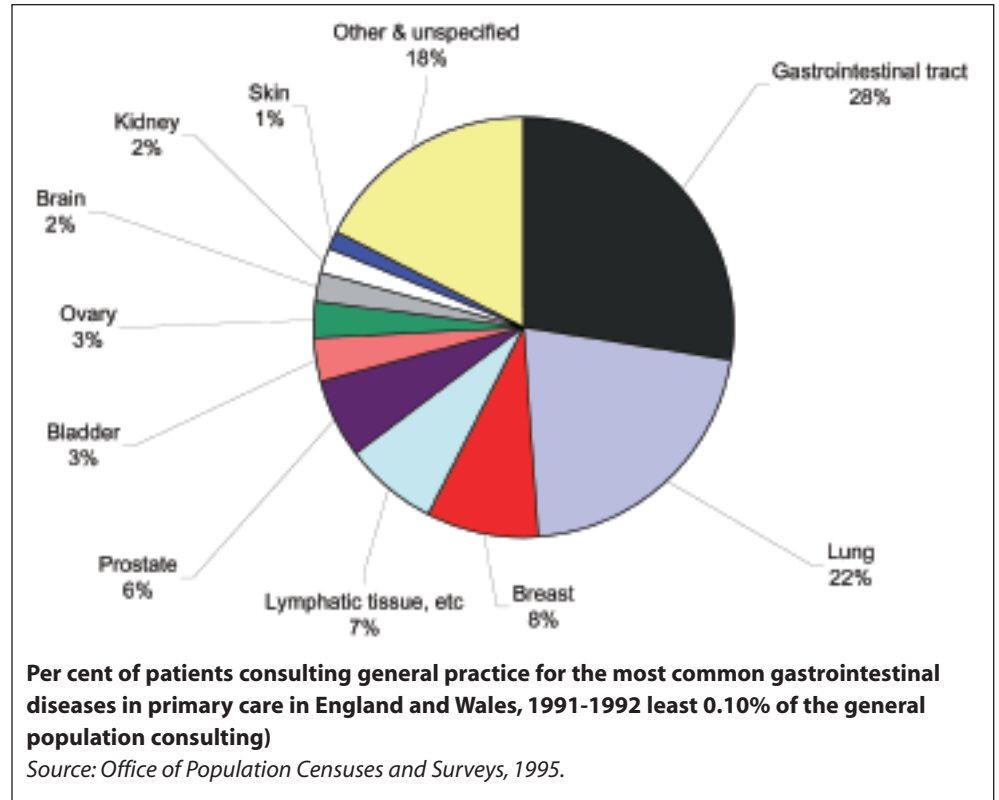
Transition arrangements are crucially important for this vulnerable group of patients. Transition clinics in which paediatric gastroenterologists and adult gastroenterologists and their multidisciplinary teams participate are to be recommended.

PRIMARY CARE

Gastroenterology accounts for about 10% of the cases seen in primary care. It has a relatively low profile as a speciality in part due to the lack of an NSF and the omission of any gastroenterological quality markers in the Quality and Outcome Framework (QOF). Between 80 – 90% of all gastrointestinal disease is managed in primary care with only a minority being referred for specialist opinion. Patients that are referred often have long-term conditions which require shared care between primary and secondary care and where a systematised chronic disease management approach can be adopted. By definition primary care is delivered close to the patient.

Despite its relative lack of prominence in primary care gastroenterology deserves importance because of the numbers of patients affected, the disproportionate costs (mainly drugs) and the numbers of gastrointestinal cancers. Given the diversity of conditions seen and the fact the majority are treated in primary care there is a strong case for greater resource and attention to be paid to GI conditions in general practice.

Chronic disease management is central to the care of a number of other conditions seen in primary care. General practice IT systems are relatively sophisticated and an approach where a register of patients is set up then prompted to attend for given interventions at set intervals would be easy to implement. Local protocols of care based on national evidence-based guidelines could easily be incorporated.



Drivers for Change

The new GP contract introduced in April 2004 has significantly changed the nature and organisation of general practice. There are future changes and uncertainties embodied in the reintroduction of a market in health and the entry of non-NHS providers of primary healthcare services. Under the new contract various incentive schemes exist to resource new models of providing care:

- The Quality and Outcome Framework assesses performance against nationally set targets and has been a potent force in implementing better, systematic care in a number of disease areas. It is hoped that dyspepsia and Coeliac Disease will be included in the revised targets to be announced in the near future. Inclusion in the QOF will provide incentives and resources for improving care in these areas.
- Locally Enhanced Schemes (LES) are locally agreed service agreements to provide a service to a set standard. Usually they are used to plug gaps in service provision or to fund innovative new ways of providing services.
- Case management and community matrons are likely to be introduced to be proactive in delivering care to vulnerable patients and to prevent admissions.

- Practice Based Commissioning (PBC) will allow practices, or more likely locality groups of practices, to commission or to deliver services in the new health market. Referral criteria for entry to secondary care and the provision of services outside hospitals are likely under PBC.

Gastro-oesophageal Reflux Disease and Dyspepsia

Implementation of the NICE dyspepsia guidelines, possibly with local variation to reflect local circumstances, should be encouraged. This requires access to appropriate *Helicobacter pylori* testing and endoscopy where appropriate. There also needs to be planning and provision for the review of dyspeptic patients.

Functional Gastrointestinal Diseases

FGID represents a major workload in primary care. The advent of new drug and non-drug treatments means that the recognition of the sub-groups of patients likely to benefit from these interventions is needed. This could be undertaken by increased training and the setting up of a General Practitioner with Special Interest (GPwSI) service.

Inflammatory Bowel Disease

IBD is a long-term condition that could be managed within a shared care protocol. Patient self-management should be supported by input from the Primary Health Care Team.

Liver Disease

Increasing numbers of liver function tests are being performed as part of the monitoring of a number of conditions and numbers of abnormal results increase as a consequence. There is a need for an evidence-based protocol for the work-up, referral and further investigation of abnormal liver function tests.

General practitioners are ideally placed to counsel and test members of high risk groups for Hepatitis C.

Alcohol

Primary care is ideally placed for screening and the early intervention of alcohol-related diseases. Out patient detoxification with support from community based services should be readily available for appropriate patients. A local alcohol harm-reduction and treatment policy should encompass both primary and secondary care.

Colorectal Cancer

Colorectal cancer screening should be supported by primary care. The management of rectal bleeding and other lower bowel symptoms should be by a shared local protocol. Access to high quality lower bowel investigations is necessary.

General Practitioner with a Specialist Interest Grade (GPwSI)

General Practitioner endoscopists have made a major contribution to endoscopy services. They are highly committed and are increasing in number.

General Practitioners have also played an important role in other areas of gastroenterological services in the role of Clinical Assistants or Hospital Practitioners.

The development of the GPSI grade will help to formalise this group, correct inequalities in pay and is to be welcomed. However, quality control in this group where independent practice may increasingly develop, is essential.

TRAINING

It is important to recognise that training must follow and cannot lead strategy. Once the strategy for delivering gastroenterological services has been defined, training requirements and trainee numbers can be more clearly assessed. Simply introducing new trainees in the absence of a clear strategy will unbalance existing training programmes and destabilise rotations.

From a medical stand point, The Royal College of Physicians manpower document "Consultants Working with Patients" suggest that to meet all the growing demands at Consultant level, one Consultant per 40,000 population will be required. This would represent a doubling or trebling of existing gastroenterological numbers. Even if agreed, this could not be done at a stroke but would need to be part of a planned expansion over the next decade.

It is necessary to recognise that the days of the all-round gastroenterologists are numbered. This follows logically from the concept that gastroenterology units will have at least half a dozen consultants with different sub-specialist interests. There must be a recognition of the absolute need for sub-specialist training.

The move to a 48 hour week is going to make it even harder to train the specialists of tomorrow whereas in the past, gastroenterologists have mostly been general physicians as well, this may be hard to sustain.

Increasingly, there will be the trend towards gastroenterologists no longer participating in non-selective general takes.

It is essential to sustain academic gastroenterology. Top quality academic gastroenterology and research are essential to underpin developments in the treatment of gastroenterological disorders and in the delivery of services. Various pressures have made it increasingly difficult for young gastroenterologists who wish to become academics. The future status of British gastroenterology will depend in no small part in sustaining and developing academic training and careers in academic gastroenterology.

ACADEMIC GASTROENTEROLOGY & RESEARCH

Academic gastroenterology, like most other clinical academic subspecialties is under increasing threat. The causes of this problem are multiple and diverse and exist both in the University environment and the NHS. Together they have resulted in a critical reduction in the number of clinical trainees interested in academic careers at a time when consultant posts have increased greatly, and opportunities for meaningful discovery in gastroenterology have never been greater. In the past decades, academic gastroenterology has been the major driver to the improvement of quality of gastrointestinal services both in the UK and elsewhere in the world; therefore the threat to clinical service development resulting from a decline in academic gastroenterology is likely to be substantial.

The report of a Working Party set up by the British Society of Gastroenterology has recently been accepted by BSG Council and its findings will be implemented over the next year. Issues for implementation are as follows:

1. The identification and recruitment of future academics in gastroenterology: There is a need to identify and encourage all undergraduates and recent graduates in all branches of medicine to consider research as a career option.

Ways in which this can be achieved will include encouraging undergraduates to attend the Society's meetings, encouraging recent graduates to engage in academic foundation years and identifying, for those interested, centres where high-quality academic training can be provided.

2. The development of young, committed academic gastroenterologists: Once individuals have identified themselves as having an interest in clinical academic gastroenterology they will need to be provided with mentoring by experienced senior clinical academics throughout the country, and enabled to share their development needs and interests together via forums provided by the BSG.
3. Clinical training programmes for academic gastroenterologists: It will be necessary to ensure that the core curriculum for clinical training is clearly identified so that academics can achieve both core competencies as clinicians as well as competencies for their future academic careers. This is likely to require identification of core plus options which are suitable for future clinical academics and therefore different from those to be achieved by full-time NHS gastroenterologists.

It is anticipated that by the implementation of the above activities, the future of academic gastroenterology can be more assured, and the benefits of clinical academic endeavour bear fruit in the development of new, more effective, clinical services.

OPTIMAL SERVICE PROVISION FOR A POPULATION OF 250,000

The Swansea review found no reliable data to demonstrate benefits from greater centralisation of service and specialists in tertiary centres, except in obvious areas such as complex liver disease, transplantation and home parenteral nutrition. Indeed evidence suggests greater benefits from providing services close to the patient which in general is the patient's choice.

We believe there are real dangers of a shift towards centralisation in destabilising the balance of services at the primary/secondary interface and impoverishing it. This would undermine the ability to provide services locally and would have a serious secondary effect on training.

It is therefore crucial to define the essential service at local level to maintain the recommended services laid out in this document. Providing a gastroenterological service requires a functional GI unit in which expertise pertinent to the broad spectrum of the specialty is represented. This includes a close working relationship with both upper and lower gastrointestinal surgeons, diagnostic and intervention radiologists, nutritionists and dietitians, gastroenterological pathologists, clinical psychologists, geneticists and physiologists.

From a medical standpoint, it is envisaged that 24 hour a day consultant cover will remain a requirement for the foreseeable future. A model provision, based on the 2005 RCP Recommendations contained in "Consultant Working with Patients" of 1 Consultant Gastroenterologist per 40,000 population and compliance with directives restricting working hours, requires units staffed by a minimum of 6 whole time equivalents (WTE) Consultants. These would provide cross cover such that an experienced Consultant was always available on call for life-threatening emergencies such as GI haemorrhage and to advise in other urgent situations.

It would be envisaged that appointments to the team would ensure teamwork among sub-specialists with individual expertise in service provision related to therapeutic endoscopy, diet and nutrition, inflammatory bowel disease, liver disease, cancer, functional motility and endocrine disorders, pancreatic and small intestinal disorders. The individual within each such unit would be relied on to liaise via his or her own specialised network with regional and supra-regional units thus ensuring the highest standard of up-to-date care within all NHS GI units.

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