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Executive Summary

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Survey of digestive health across Europe: Final report

Introduction

United European Gastroenterology (UEG) which represents gastroenterology and hepatology and its sub-disciplines across Europe relies on accurate and up to date information on the burden of gastrointestinal diseases in Europe, the availability and quality of diagnostic and therapeutic services and the economic impact of these diseases across the member countries of the European Union to inform its strategy in advising relevant agencies on future clinical services and research priorities. Determining the trajectory of the morbidity and mortality of digestive diseases is vital in planning health services for the future and in making the case for investment in research where there are clear gaps in knowledge. In addition there are marked economic differences across the member nations in Europe and this is reflected in the funding available to support health services, making it highly likely that there are important disparities in the accessibility to high-quality healthcare.

In September 2012 the UEG Council accepted a proposal from the UEG Future Trends Committee to commission a detailed survey of digestive health across Europe. The Future Trends Committee developed an outline framework for the study, following which there was an open, competitive process across Europe to identify a competent research group to undertake the project. The contract was awarded to an experienced group within the College of Medicine, Swansea University, United Kingdom, and the project was formally initiated in April 2013.

The research group at Swansea has worked closely with the Committee, including an interim update meeting with the Committee in October 2013. The Committee also had the opportunity to make specific comments on a draft final report submitted in May 2014; a final report, *Survey of Digestive Health Across Europe* was received in August 2014. The final report is organised into two parts: Part 1, *The burden of gastrointestinal diseases and the organisation and delivery of gastroenterology services across Europe* and Part 2, *The economic impact and burden of digestive disorders*. We present here the executive summaries of the two parts of the survey, but the full report can be found on the UEG journal website. It is anticipated that several shorter publications will follow, focusing on some specific topics of particular importance and interest.

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Executive summary: Part 1: The burden of gastrointestinal diseases and the organisation and delivery of gastroenterology services across Europe

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Purpose of the report

This report has been commissioned by the United European Gastroenterology department. Gastroenterology is a speciality that tends to receive relatively little attention from a policy perspective and, compared with other specialities, attracts relatively little charitable research funding. One of the remits of United European Gastroenterology is to raise the political and public awareness of gastrointestinal disorders throughout Europe. To facilitate this, this report is intended to draw together the evidence and provide up to date information on the public health burden of gastrointestinal disorders, their human consequences, their economic burden and the organisation and delivery of gastroenterology services across Europe, including disease screening programmes.

This report does not seek to replicate existing guidance, which has been published for many gastrointestinal diseases, but draws on evidence contained in some of these documents. The first part of this report covers the burden of gastrointestinal diseases and the

organisation and delivery of gastroenterology services across Europe and the second addresses the economic burden of gastrointestinal diseases, including patient health related quality of life. The report is intended to be of value to patient groups, clinicians, politicians, managers and civil servants, especially those responsible for developing or delivering services to patients with gastrointestinal disorders across Europe.

Methods

This review covers the 28 countries that are member states of the EU, along with Norway, Switzerland, Liechtenstein and Russia and is focused on the most recent years since 2000, although for comparative purposes, some sections of the review also cover the 1990s, the 1980s and the 1970s. The review examines all major gastrointestinal disorders including gastro-oesophageal, intestinal, hepato-biliary and pancreatic diseases, gastrointestinal malignancies and other gastrointestinal disorders and related conditions. Systematic reviews of the medical literature were undertaken, along with searches of grey literature, reports, websites and other data sources to assess the public health and economic burden of gastrointestinal disorders and the organisation and delivery of services in gastroenterology.

Main findings

Burden of disease

- Incidence and prevalence data across Europe are compiled routinely only for gastrointestinal cancers and certain communicable diseases, so that most of the available evidence on the burden of gastrointestinal disorders is based on a large variety of individual studies, often with patchy population coverage and varying data quality. The evidence base for assessing the prevalence and public health burden of most (non-communicable) liver diseases is particularly weak. There is an absence or major lack of evidence from eastern Europe on the incidence or prevalence of many gastrointestinal disorders.
- There have been increases in the incidence of most gastrointestinal disorders in Europe which have major implications for future healthcare provision. These include upper gastrointestinal bleeding, Barrett's oesophagus, oesophagitis, inflammatory bowel disease (in most countries), coeliac disease, diverticular disease, alcoholic liver disease, primary biliary cirrhosis, primary sclerosing cholangitis, gallstone disease, hepatitis B and C infections (in some countries), acute and chronic pancreatitis, oesophageal, colorectal and pancreatic cancer.
- The incidence and prevalence of many gastrointestinal disorders are highest among older people. With an ageing European population, this will also lead to future increases in disease burden across Europe.
- The incidence of paediatric disorders such as inflammatory bowel disease, coeliac disease and eosinophilic oesophagitis is also increasing in many European countries.
- Although under-reported in many eastern European countries, the incidence or prevalence of many gastrointestinal disorders is often increased in these countries when compared with other regions of Europe. These disorders include gastro-oesophageal reflux disease, helicobacter pylori infection, acute pancreatitis and oesophageal, gastric, pancreatic and gallbladder cancer. Mortality from (non-malignancy) gastrointestinal diseases overall is highest in eastern and north-eastern Europe and lowest in parts of Scandinavia and the Mediterranean islands.
- There are important social inequalities for many gastrointestinal disorders, within countries as well as across Europe, including upper gastrointestinal bleeding, gastro-oesophageal reflux disease helicobacter pylori, peptic ulcer, liver cirrhosis, hepatitis B and C, acute pancreatitis, oesophageal and gastric cancer.
- Both Crohn's disease and ulcerative colitis show east: west as well as north:south gradients in incidence with highest rates usually in northern or western regions of Europe.
- Inflammatory bowel disease, gastro-oesophageal reflux disease and hepatitis C have a major impact on work productivity, absenteeism and work experiences across European countries. Inflammatory bowel disease and hepatitis C have also been shown to have a major impact on health-related quality of life across Europe.

Mortality

- Gastrointestinal cancer is the leading cause of cancer death in Europe. It is also the most common cancer in men and the second most common in women after breast cancer.
- One and five-year survival following diagnosis with major gastrointestinal malignancies is usually highest in central and western European countries. Survival appears to be worse in parts of eastern Europe, although there is still a lack of data from some eastern European countries.
- Population-based mortality for colorectal cancer has been falling over several decades in almost all western, northern and central European countries. It is continuing to increase in many eastern European countries – particularly for men – and in some parts of southern Europe.
- Projections for colorectal cancer mortality indicate continuing reductions in mortality over the next five

to 10 years in northern and western Europe, but for mortality to then level off or increase in some countries over the subsequent 10 years. Projections for eastern Europe are for an increase or static level of mortality in the next five to 10 years, but then a subsequent reduction. Gastric cancer mortality is expected to continue falling throughout Europe – but with levelling mortality or increases in the longer term for parts of western Europe – while oesophageal cancer mortality is also forecast to fall, although with interim increases in some eastern European countries.

Human resources

- There is an absence of accurate, up-to-date workforce data across Europe relating to the number of gastroenterologists per country and per head of population.
- There is an absence of evidence from European countries on both the content and quality of postgraduate and undergraduate education and training in gastroenterology. The experience in specialist areas of gastroenterology varies between countries and does not always follow the European curriculum of gastroenterology.

Service provision

- Colorectal cancer screening programmes are now well established in the majority of European countries but their impact on mortality has not yet been established fully. Most countries are still within the first 10 years of their programmes so full analysis will take several years. It is also unclear whether the introduction of colorectal screening programmes across Europe may disadvantage other patient groups that require regular endoscopy services.
- Upper gastrointestinal bleeding is managed variably across Europe with a lack of consensus on best practice. Differing policies are in place regarding the use of pharmacological agents as well as the timing of endoscopy. Access to out of hours and weekend endoscopy services varies across countries and centres, although patient outcomes often do not appear to be affected by this.
- Endoscopy services are not currently viewed as a priority policy and service area across Europe despite its expansion and this has uncertain implications for meeting future service demand. Nurse endoscopists have become increasingly an important part of medical workforces and a core curriculum has provided a benchmarking process to ensure quality assurance in endoscopy services. The impact on increased nursing numbers on doctor training remains unclear.
- The role of the inflammatory bowel disease nurse is increasingly important in managing patient treatments and is considered as an essential part of the inflammatory bowel disease team in many countries. Multi-disciplinary clinics are ad hoc in most European countries, and tend to occur only in the larger hospitals.
- The impact of inflammatory bowel disease on paediatric patients' social and psychological development is often overlooked. Transitional inflammatory bowel disease services are crucial to effective care for young adults with inflammatory bowel disease, but structured services are often only available in larger or regional hospitals.
- European inflammatory bowel disease registries are increasingly being used to monitor patient outcomes and will form an important analytical tool in producing future clinical guidelines.
- Very little data currently exist reflecting individual European country adherence to clinical guidelines, as well as patient outcomes relating to management.
- Despite national and international guidelines for Barrett's oesophagus, there remains considerable variability in compliance to guidelines with regards screening intervals, biopsy protocols, reporting and therapies. Changes in more recent guidelines could have implications for screening intervals and therefore the demand on endoscopy services.
- Contention remains over the absolute benefits of Barrett's oesophagus surveillance programmes.
- Screening is not cost-effective and intervention for high grade dysplasia is controversial. Endoscopic resection or therapies have become the treatment of choice for high grade dysplasia and early cancer detection across Europe and have resulted in reduced morbidity for patients.
- Alcohol concern is a major public health concern with increasing rates of end stage liver disease in many countries, which have led to public health campaigns and policies aimed at addressing drinking patterns. However, there is currently a lack of evidence as to the services offered to patients with alcohol-related diseases across Europe.
- The demand for liver transplantation is increasing and many European countries are attempting to address this need with changes in public health and ministerial policies and law. Several countries operate as networks to maximise the use of potential organs, but individual countries still operate different allocation policies for liver transplantation.

Economic burden

- Major difficulties in identifying and measuring the economic and health-related quality of life burden of gastrointestinal disorders across Europe include variations in measurement and reporting of economic costs and different approaches to financing and providing healthcare in different countries.
- There is very little or no information available about the economic impact of gastrointestinal disorders from countries other than France, Germany, Italy, the Netherlands, Norway, Spain, Sweden and the UK.
- The cost of inflammatory bowel disease care has increased significantly over the past decade, mainly through the increased use of biological therapies. Mainland European treatment costs are higher than in the UK with a more aggressive, top down approach for larger numbers of patients with IBD.

Recommendations for further research

- This report has collated much evidence about the human, public health and economic burden of gastrointestinal diseases and the provision of gastroenterology services across Europe. Hopefully it will help to improve healthcare and reduce inequalities.
- There is a general need for further research into the incidence, prognosis and public health burden of many gastrointestinal disorders across Europe, and a particular need for more studies from eastern Europe, along with pan-European and multinational studies.
- There is generally poor reporting of health-related quality of life and economic data, and a lack of clarity about economic cost data. Further initiatives are required, either directly by funding or indirectly through lobbying, to encourage research that will fill these gaps. This would also help economic evaluations that will inform decision makers about the merits of therapeutic interventions.
- With the increasing availability of electronic medical records and research using electronic health data, particularly in the UK, Scandinavia and Germany, there should be coordinated efforts to use data recorded at the point of care to inform research into the personal, public health and economic burden of GI diseases across all European countries. There would be considerable benefits to such research if clinical data collection across Europe could be standardised, using a common terminology such as SNOMED-CT, and common patient record structure such as that recommended by the Academy of Medical Royal Colleges in the UK.
- Research funding for more pan-European studies that establish the economic and health-related quality of life consequences of digestive disorders should aim to further cross country comparisons. Thus, whenever possible, the data should be collected and presented in a standardised way to enable more informed synthesis. An uncoordinated approach will continue the fragmented picture that exists at present, and pan-European or multinational studies using standardised methodology will be particularly valuable.

Specific areas for further research

- There is a particular need to address the extremely weak evidence base relating to the prevalence and public health burden of most liver diseases, as well as gallstones, diverticular disease and Barrett's oesophagus.
- There is a general lack of evidence from across Europe regarding the provision of services for patients with alcohol-related disease. In particular, as minimal alcohol pricing levels are introduced across Europe, research will be required to assess the impact of these policies on alcohol-related hospitalisations and mortality.
- Further work is required to determine whether the Child-Turcotte Pugh (TCP) or the Model for End-Stage Liver Disease (MELD) score is the optimal tool for predicting the need for, and outcomes following liver transplantation.
- For both non-variceal and variceal upper gastrointestinal bleeding there is a need to analyse current evidence, in particular to inform consensus guidelines, and to clarify the optimal timing for endoscopy after hospitalisation.
- The impact of inflammatory bowel disease on the social and psychological development of paediatric patients is often overlooked and should be explored. An absence of published work on the benefits of transitional clinics for inflammatory bowel disease should be addressed by interested and specialist European groups.
- Further research will be required to assess whether recent changes in guidelines for Barrett's oesophagus will have any effects on patient outcomes.
- Updating existing workforce data on the number of gastroenterologists per country and per head of population must be a priority in order to plan future services and to identify areas of need both

within individual countries and across European regions. Further research is also required to model workforce needs to ensure that endoscopy services are maintained for groups such as inflammatory bowel disease patients and high risk cancer surveillance groups.

- There is a need to map different national curricula for postgraduate and undergraduate education and training in gastroenterology with a European curriculum, and also address the predicted future needs of the European population.