

# Survey of digestive health across Europe: Final report. Part 2: The economic impact and burden of digestive disorders

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## Introduction

Digestive diseases – gastrointestinal and liver disorders – are common across Europe, causing more than 500 000 deaths in 2008 in the 28 EU member states (and more than 900 000 deaths in the whole of Europe, including Russia and other non-EU states). However, United European Gastroenterology (UEG) believe that these diseases are poorly understood, have usually attracted relatively little attention from a policy perspective and do not attract significant research funding, in comparison with many other disciplines. One of the remits of the UEG is to raise the political and public awareness of gastrointestinal disorders throughout Europe. To facilitate this, accurate and up to date information is required on the human and health consequences and on the economic burden of digestive disorders.

## Aims and objectives

Specific research objectives set by the UEG were:

1. Documentation of the impact on health-related quality of life (HRQOL) of people with digestive diseases.
2. Documentation of the reported healthcare costs for digestive disorders to include comparisons between national systems.
3. Comparison of healthcare systems engaged in the management of digestive disorders in Europe and their respective economies.
4. Development of a rationale for European research support, in respect of economic and HRQOL burden in the medium and long-term future.

## Methods

Structured literature searches were undertaken between July and September 2013. All database searches were restricted to literature published after 2006. This was because a prior publication<sup>1</sup> had undertaken a similar

search prior to 2006 with few findings reported. After all searches had been carried out 44,444 papers were identified as potentially suitable for screening and after reviewing titles, abstracts and full papers we had 37 to be included in the final HRQOL review. Whilst this was not a systematic review in the formal sense, as we were simply seeking reports of the economic burden and/or burden of digestive diseases on HRQOL, we adhered as far as applicable to the PRISMA statement methodology.

Of the 17,895 papers identified for the economic burden search after screening we found 33 papers to include in this report. As well as the literature search additional searches were undertaken directly on the websites and also via direct contact with relevant departments within organisations which were supplemented and validated by UEG members. Grey literature and searches of websites for publications were made, government reports, other reports and data collected by international and national organisations and societies for digestive disease were inspected and analysed to obtain information.

## Findings

There were a good number of studies reporting measurements of HRQOL in digestive diseases, using the Short Form 36 (SF-36) instrument. However, despite the fact that the EQ-5D is a standard approach used in many jurisdictions there were few publications reporting HRQOL burden measured by the EQ-5D, another generic HRQOL instrument which also incorporates measurement of preference-based ‘utility’. This may be because the EQ-5D is primarily used to estimate scores for specific health states/disease states to use in economic evaluation rather than burden of disease. We found reports of the impact on HRQOL where researchers had used condition (disease) specific measures. Specifically we found that the European Organisation for Research and Treatment of Cancer HRQOL questionnaire (EORTC QLQ C30) – an HRQOL instrument used widely to measure HRQOL

impact in cancer patients within trial and studies – was used in most of the research studies investigating the impact of digestive neoplasms on HRQOL. Cancer-site specific modules are available to supplement the EORTC QLQ-C30 for several digestive neoplasms and were sometimes used to assess the impact of treatment on HRQOL.

Whilst research using disease-specific measures can identify and report the impact of a disease on HRQOL in a sensitive and specific way it is not helpful in establishing a disease burden that can be understood in population terms. As our research found that the HRQOL literature relating to digestive diseases was sparse – or even absent – in many countries, we have included disease specific data from these reports.

We scanned health technology assessments (HTAs) for burden data in the countries which had undertaken evaluation of cancer drugs that are used in digestive neoplasms at varying stages of disease. Monoclonal antibodies such as infliximab used to treat ulcerative colitis and Crohn's disease have also been the subject of HTA studies. Reporting the complexities and outcomes of these evaluations was beyond the scope of this project. However, it is clear from our scanning that relatively expensive drugs for digestive diseases which fall under the scrutiny of HTA bodies do not always get positive outcomes and approvals for use in jurisdictions that use HTA as a 'hurdle' prior to funding and access for prescribing.

A recent World Health Organisation (WHO) European Health Report comments that the trend towards increasing income levels seen in the past decades is now challenged by the current economic downturn, which is affecting most European countries. The strong association between average per capita income and mortality levels is well established. Decreasing income and increasing disease burden represent an important challenge because of the scale of the disease burden, and its negative impact on current and future economic development. The report also suggests that various mortality indicators show similar patterns of health inequalities across the EU.

Income inequalities between EU countries affect the level of healthcare spending. Total healthcare expenditures in EU countries vary between US \$ 1 and 400 billion per annum. The top six countries which on average spend more than US \$ 100 billion per annum are Germany, France, United Kingdom, Italy, Spain and the Netherlands. In 2012 Germany spent US \$ 383 billion on healthcare. Countries that spend between US \$ 10–100 billion on the healthcare are Belgium, Sweden, Austria, Norway, Denmark, Poland, Finland, Ireland, Greece, Portugal and the Czech Republic. Among the countries which spend less than US \$ 10 billion on the

healthcare per annum are Hungary, Romania, Slovakia, Slovenia, Luxemburg, Bulgaria, Lithuania, Cyprus, Latvia, Estonia and Malta.

General government expenditures on healthcare vary between 43% in Cyprus and 86% in Denmark in 2012. Personal out of pocket expenditure on health varied significantly between 6% in the Netherlands and 49% in Cyprus in 2012.

Whilst generally research into the burden of digestive disease in Europe is patchy and inconsistent in terms of methods and outcome measures, three very useful, exemplar, pan-European studies examine the impact of gastro-oesophageal disease (GERD), hepatitis C (HCV) and inflammatory bowel disease (IBD) on work productivity, impairment at work/presenteeism and work experiences. GERD has an impact on average absenteeism and on work productivity. The average monetary impact of GERD-related work absenteeism and presenteeism was substantial in all countries studied (from EUR 55/week per employed patient in the UK to EUR 273/patient in Sweden). Reductions in productivity in daily life of up to 26% were observed across European countries.

People with HCV ( $n=286$ ) had more work impairment compared with people without HCV (30% vs. 18%,  $p < 0.001$ ), more impairment in non-work activities (34% vs. 28%,  $p < 0.05$ ), and more annual physician visits per person (19.8 vs. 13.3,  $p < 0.001$ ). Estimated indirect and direct costs were EUR 2956 ( $p < 0.01$ ) and EUR 495 ( $p < 0.001$ ) higher than in matched controls, respectively. Work was significantly affected by IBD: 44% reported to have lost a job (or had to quit a job) because of IBD.

Twenty-five percent of people with HCV stated that they have received complaints or unfair comments from superiors and/or colleagues about work performance in relation to their disease, 21% stated that they have been discriminated in the workplace.

## Conclusion

Since the publication by Williams et al. there is a greater absolute number and range of both economic and HRQOL studies reported. Overall the economic burden and HRQOL burden picture is fragmented and the ability to compare research from different countries is compromised, because of differing methods and lack of detail in reporting. Different approaches to financing and providing healthcare add further complexity and difference. What reports or data we have found are limited in comparability.

Researchers in Spain, Finland and the UK undertook studies using the SF-36 to establish how the impact on HRQOL in people with IBD and HCV compared with population norms i.e. the HRQOL of the

general population measured by the SF-36. In all cases the disease caused impairment of HRQOL relative to population norms. This is invaluable data and enables the HRQOL burden of the disease to be understood and in which domains of HRQOL the diseases have most impact. The SF-36 is a widely used instrument and most major countries in Europe have undertaken research reporting population norms.

Unfortunately, for the few countries where data is relatively richer, the project scope did not include formal economic modelling to be used to combine both the epidemiology data and economic cost data. For digestive diseases where cost and epidemiological burden appear high – for example Hepatitis C – and for which HRQOL data are available, IBD for example, undertaking such an exercise to ensure awareness of the full burden in comparison with other well funded areas of disease research could be worthwhile to make the case for similar levels of research findings. A short term research recommendation is to use the data identified in this research and undertake economic modelling for priority diseases identified by UEG.

With the existing data that have been gathered in this research, integrating the published epidemiological, cost and HRQOL data for the digestive diseases that

are priorities to address and where the data exist, use economic modelling to create a true burden of illness study for the source country, could move the UEG agenda forward in that country and the EU region.

A coordinated approach to research (and importantly funding for research) would be ideal and would enable researchers to build on the data that exists and mitigate the somewhat fragmented picture that exists at present. Research funding for more pan-European studies that establish the economic and HRQOL consequences of digestive diseases would further the understanding of these diseases in terms that enable cross disease and cross country comparisons. Research could then be encouraged and prioritised where there is greatest impact of either or both economic or HRQOL burden. The funding for improved management and/or new treatments may be realised through this greater understanding.

In an era where there is increasing availability of electronic medical records and the ability to undertake research using real world data – particularly in the UK, Sweden and Germany – research into the current burden of digestive diseases could be undertaken without resorting to expensive studies and active primary data collection.