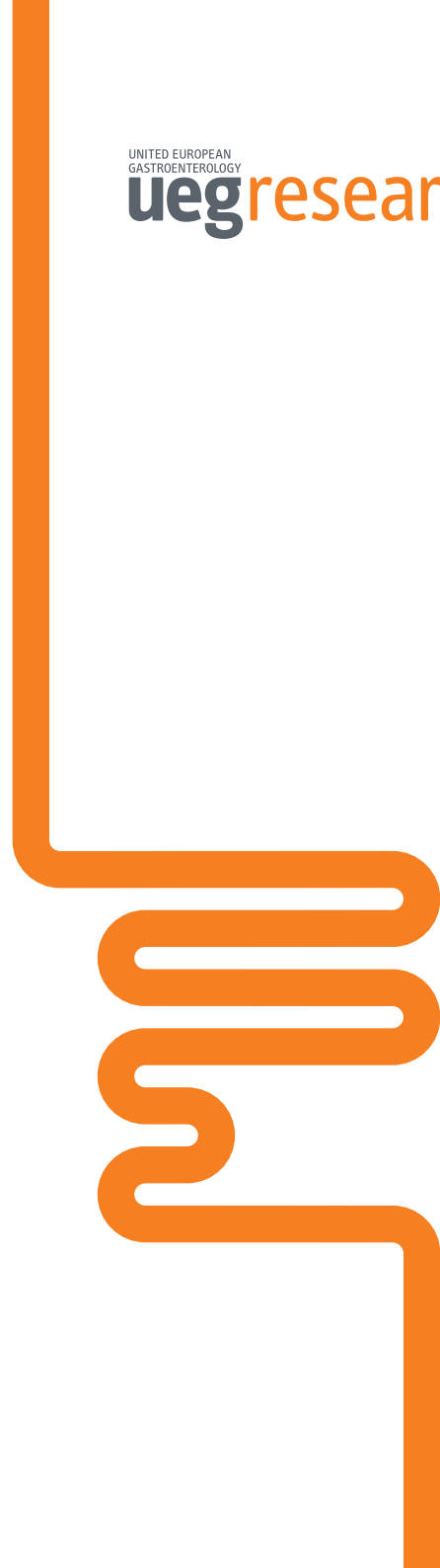


The Survey of Digestive Health Across Europe

Highlighting changing trends and healthcare
inequalities in GI and liver disease



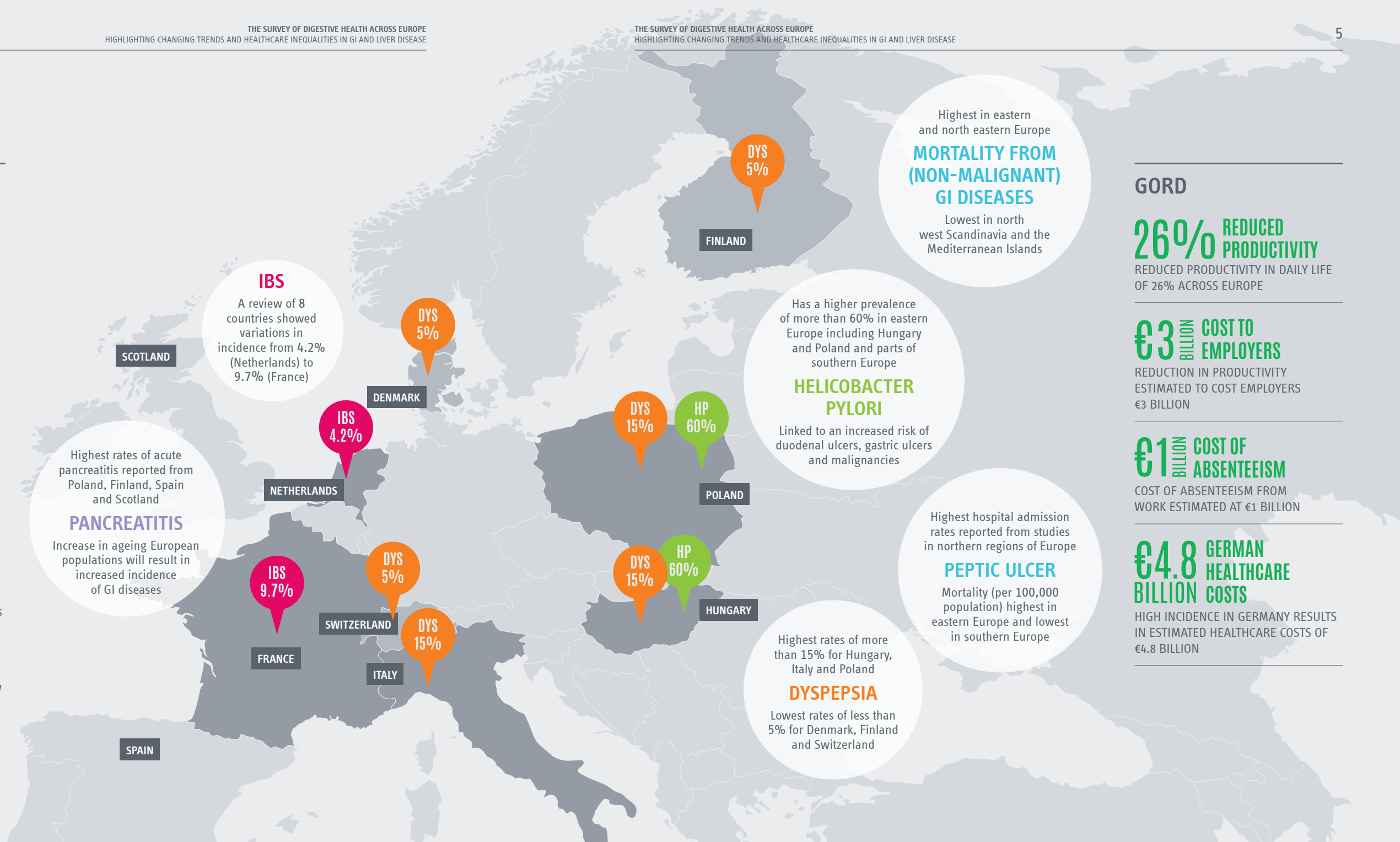
Gastrointestinal (GI) disorders

The GI disorders, dyspepsia, gastro-oesophageal reflux disease (GORD), peptic ulcers, *Helicobacter pylori* (*H.pylori*) infection, oesophagitis, irritable bowel syndrome (IBS) and pancreatitis are common and costly conditions, yet they are often under-reported and their true burden is difficult to quantify.

Current data suggest that the incidence and prevalence of these GI disorders, which includes the most common functional disorders, are generally increasing, with the highest rates reported in eastern European countries and in less affluent parts of western Europe. Many of these conditions, if inadequately treated, can lead to potentially life-threatening complications. Mortality rates are highest in eastern and north eastern Europe and lowest in north west Scandinavia and the Mediterranean islands.

Very little information exists on the economic burden of these disorders across Europe, however, direct costs associated with frequent physician visits and medical treatments and high rates of complications and hospitalisation, and indirect costs due to substantial levels of personal disability, work absenteeism and loss of productivity are all likely to contribute to their sizable socioeconomic burden.

With a rising prevalence and high rates of morbidity and mortality in less affluent parts of Europe, these common and costly conditions exert a sizable socioeconomic burden across the continent.



Inflammatory bowel disease (IBD)

The inflammatory bowel diseases, Crohn's disease and ulcerative colitis, are common, chronic inflammatory conditions that primarily affect young people in adolescence and early adulthood. The incidence and prevalence of IBD have increased in the last few decades throughout Europe, with significant geographic variations reported. The highest incidence rates are observed in Scandinavia and the United Kingdom, while the lowest rates are seen in southern and eastern Europe.



**INCREASE
IN THE
WEST**

DRAMATIC SUSTAINED INCREASE IN INCIDENCE IN MANY WESTERN COUNTRIES



**INCREASE
IN THE
EAST**

RECENT INCREASE IN INCIDENCE IN EASTERN EUROPE PUTTING PRESSURE ON HEALTHCARE SYSTEMS



**FINANCIAL
BURDEN**

HEAVY FINANCIAL BURDEN TO WESTERN HEALTHCARE SYSTEMS

**MORE COMMON IN
NORTH
& WEST
EUROPE**

MORE COMMON IN NORTHERN AND WESTERN REGIONS OF EUROPE, ESPECIALLY FOR CROHN'S DISEASE



A NORTH: SOUTH AND AN EAST: WEST GRADIENT IN THE INCIDENCE OF BOTH CROHN'S DISEASE AND ULCERATIVE COLITIS.



AVAILABILITY OF DRUGS, INVESTIGATIONS AND TREATMENT STRATEGIES VARY SIGNIFICANTLY ACROSS EUROPE

Many people with IBD have frequent relapses or continuous active disease that often results in complications requiring hospitalisation and/or surgery. Treatment strategies vary widely across Europe, which is likely to affect cost and clinical outcomes. The long-term impact of IBD in terms of direct and indirect costs and the burden on the individual is huge. Direct costs associated with IBD have increased significantly over the past decade, primarily as a result of the increased use of biological therapies.

The Survey reported that the impact of IBD on the social and psychological development of paediatric patients is often overlooked and should be explored further.

Worrying increases in the incidence and prevalence of IBD, inconsistent treatment practices, and high rates of complications contribute to a poor outlook for young people with IBD in Europe.

Oesophageal and gastric cancer

Oesophageal and gastric cancer account for around 6% of all cancers in men and 3% of all cancers in women. Oesophageal cancer typically affects people aged between 60 and 80 years, with the most important risk factors being severe, longstanding gastro-oesophageal reflux disease (GORD), smoking and heavy alcohol consumption. There were 34,534 new cases of oesophageal cancer recorded in the EU in 2012, with an incidence rate of 6.9 per 100,000 population. The incidence is highest in north eastern European countries.

GASTROINTESTINAL CANCER INCIDENCE...

LEADING CAUSE OF CANCER DEATH IN EUROPE

MOST COMMON MALE CANCER



THE MOST COMMON CANCER IN MEN AND THE SECOND MOST COMMON IN WOMEN

LOWEST INCIDENCE SCANDINAVIA

LOWEST REPORTED INCIDENCE FROM SCANDINAVIA AND NORTH WEST EUROPEAN COUNTRIES

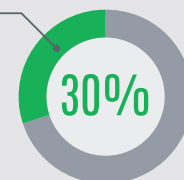
684,000 CASES

INCIDENCE OF 684,000 CASES ACROSS 27 EU MEMBER STATES IN 2012

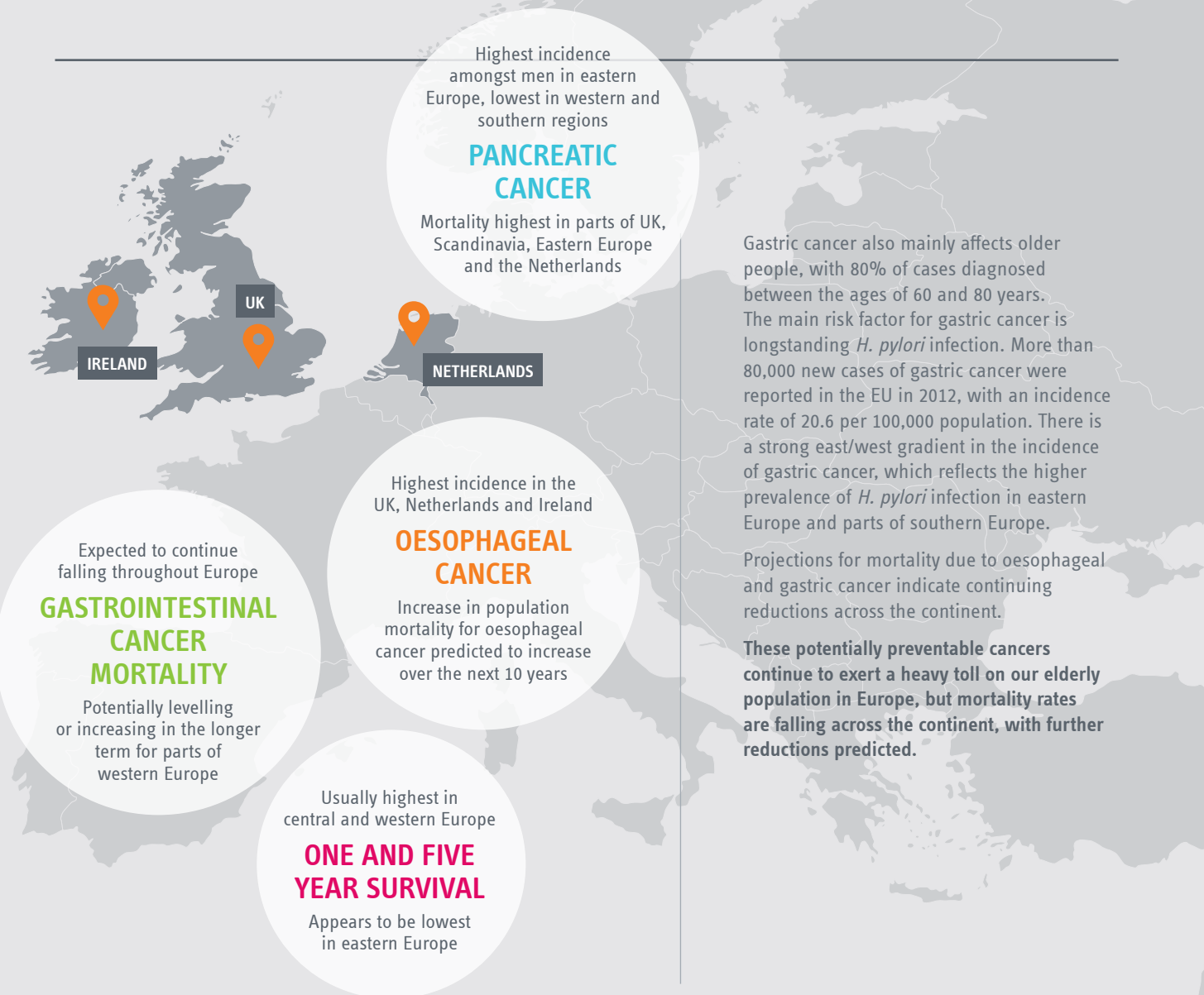
HIGHEST INCIDENCE NORTH EAST EUROPE

HIGHEST REPORTED INCIDENCE FROM NORTH EASTERN EUROPE

ALL NEW MALE CANCERS



ACCOUNTED FOR 30% OF ALL NEW CANCERS AMONG MEN AND 25% AMONG WOMEN



Colorectal cancer

Colorectal cancer (CRC) is the most common GI cancer in Europe, with 342,137 new cases recorded in the EU in 2012. The incidence of CRC is higher in men than in women. The main risk factors for CRC include a family history of the condition, the hereditary conditions, Lynch syndrome or familial adenomatous polyposis, and long-term IBD. Other risk factors include diabetes, diets low in fibre and high in saturated fats, a sedentary lifestyle, exposure to radiation, heavy alcohol consumption and tobacco smoking.

The prognosis for CRC is relatively good compared with other GI malignancies and there is relatively little variation in reported survival across most European countries. Population-based mortality for CRC has been falling for several decades in most western, northern and central European countries. However, mortality is continuing to increase in many eastern European countries – particularly in men – and in some parts of southern Europe.

MOST COMMON GI CANCER
COLORECTAL CANCER IS THE MOST COMMON TYPE OF GI CANCER IN EUROPE

342,137 NEW CASES

342,137 NEW CASES (14.3% OF ALL CANCERS) RECORDED IN THE EU IN 2012

HIGHER MALE INCIDENCE

INCIDENCE HIGHER AMONGST MEN (79 PER 100,000) THAN WOMEN (54)

68 INCIDENCES PER 100,000

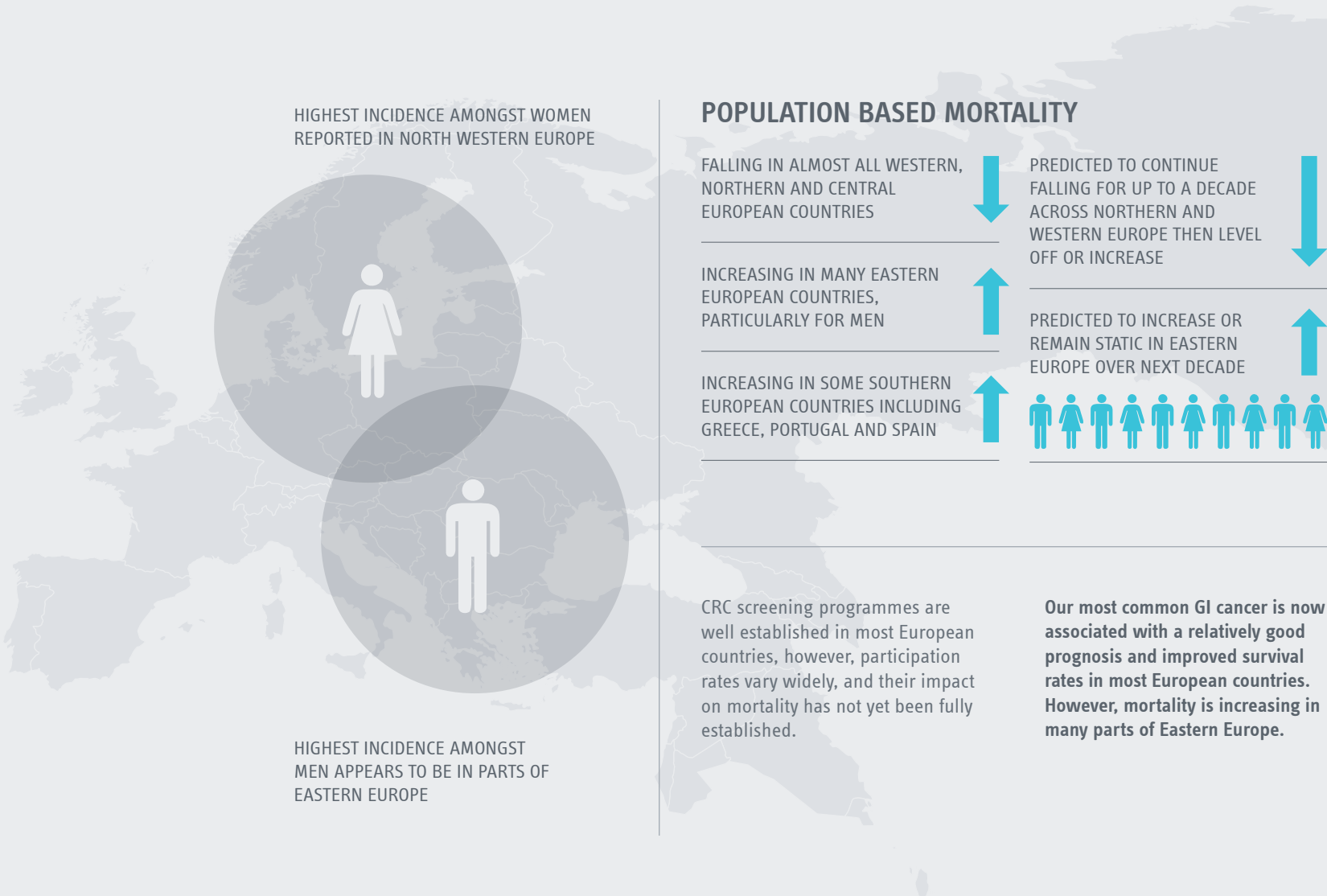
INCIDENCE RATE OF 68 PER 100,000 POPULATION



ACCOUNTS FOR ABOUT HALF OF ALL GI MALIGNANCIES IN EUROPE

£480 MILLION

ANNUAL COST OF TREATMENT IN THE UK ALONE TOTALS OVER £480 MILLION



Liver disease

Chronic liver disease has been estimated to affect almost 30 million people in the EU, although difficulties obtaining data from individual countries hinder the global evaluation of the burden of liver disease in Europe. Chronic liver disease is caused by a range of conditions that result in liver injury and dysfunction, including heavy alcohol consumption, hepatitis B or C infections, exposure to certain drugs and toxins, and metabolic syndromes related to being overweight and obesity.

Chronic alcohol consumption is the primary cause of chronic liver disease in Europe, although, in some regions, hepatitis B and C infections are also major risk factors. Alcohol consumption decreased during the 1990s, but increased steadily during the last decade to reach hazardous levels in many European countries. Mortality from chronic liver disease is well documented in Europe, with the highest rates reported in eastern and north eastern countries. Liver disease caused by alcohol consumption is by far the most lethal form of the condition. The prognosis for people with late-stage liver disease remains dismal and has not improved substantially over the last 50 years.

Alcohol consumption has reached hazardous levels in many European countries, contributing to the growing burden of liver disease. The prognosis for people with late-stage liver disease remains dismal.

ALCOHOL-RELATED LIVER DISEASE

INCREASES IN HOSPITALISED CASES OF ALCOHOLIC LIVER DISEASE OVER THE LAST TWO DECADES ARE WIDESPREAD

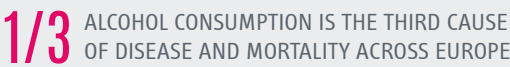


ACROSS EUROPE ALCOHOL IS GENERALLY REGARDED AS THE LEADING CAUSE OF LIVER DISEASE

EUROPE HAS THE HIGHEST LEVELS OF ALCOHOL DRINKERS IN THE WORLD



EASTERN EUROPEAN COUNTRIES HAVE EXPERIENCED INCREASED LEVELS OF CONSUMPTION OVER RECENT YEARS WHERE HARMFUL DRINKING AND ALCOHOL ABUSE IS HIGHER THAN OTHER PARTS OF EUROPE



THERE IS CONCERN THAT YOUNGER EUROPEANS ARE DRINKING HEAVILY AND MORE OFTEN

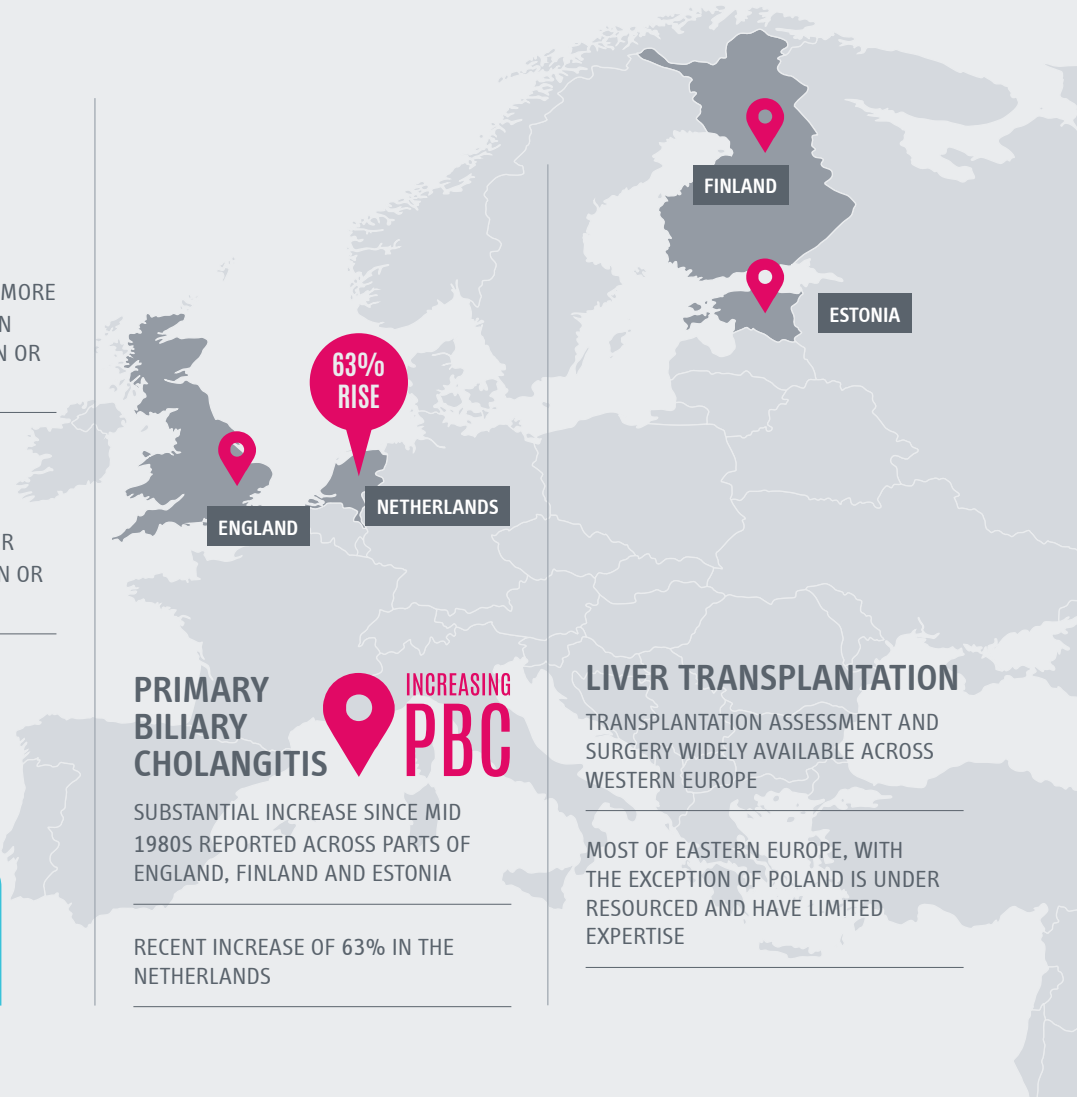
CHRONIC LIVER DISEASE



HIGHEST RATES OF MORTALITY OF MORE THAN 30 PER 100,000 POPULATION ARE MOSTLY FROM SOME EASTERN OR NORTH EASTERN COUNTRIES



LOWEST RATES OF LESS THAN 8 PER 100,000 MAINLY IN SCANDINAVIAN OR MEDITERRANEAN COUNTRIES.



PRIMARY BILIARY CHOLANGITIS

SUBSTANTIAL INCREASE SINCE MID 1980S REPORTED ACROSS PARTS OF ENGLAND, FINLAND AND ESTONIA

RECENT INCREASE OF 63% IN THE NETHERLANDS

LIVER TRANSPLANTATION

TRANSPLANTATION ASSESSMENT AND SURGERY WIDELY AVAILABLE ACROSS WESTERN EUROPE

MOST OF EASTERN EUROPE, WITH THE EXCEPTION OF POLAND IS UNDER RESOURCED AND HAVE LIMITED EXPERTISE

Hepatitis B and C virus infections

SCREENING

SCREENING IS NOW COMMON PRACTICE IN HIGH RISK GROUPS AND PREGNANT WOMEN ACROSS EUROPE



HIGHEST IN ROMANIA & GREECE

HIGHEST REPORTED INCIDENCE OF HEPATITIS B IN ROMANIA AND GREECE

HEP B

90%

HEPATITIS B IS TRANSMITTED FROM INFECTED MOTHERS TO UP TO 90% OF BABIES ACROSS EUROPE

IN WESTERN EUROPE, HEPATITIS C HAS BEEN REPORTED TO LEAD TO...

70%

70% OF ALL CASES OF CHRONIC HEPATITIS,

40%

40% OF ALL CASES OF LIVER CIRRHOSIS, AND

60%

60% OF ALL CASES OF HEPATOCELLULAR CANCER



HIGHEST IN ITALY & ROMANIA

HIGHEST REPORTED INCIDENCE OF HEPATITIS C IN PARTS OF EASTERN AND SOUTHERN EUROPE INCLUDING ITALY AND ROMANIA

21% DISCRIMINATED AGAINST IN THE WORKPLACE

THROUGHOUT EUROPE, 21% OF THOSE WITH THE HEPATITIS C VIRUS (HCV) HAD BEEN DISCRIMINATED AGAINST IN THE WORKPLACE



LEADING CAUSE OF LIVER TRANSPLANTATION



The liver diseases, due to hepatitis B and C viruses, affect millions of Europeans, with the highest prevalence found amongst those who inject drugs. Hepatitis B is spread primarily through unprotected sex and contaminated needles, although perinatal transmission remains an important source of infection across Europe. While most cases of hepatitis C are found amongst intravenous drug users, blood transfusions, other medical procedures, unprotected sex, tattooing equipment and transmission from mother to baby are also important modes of virus transmission. Co-infection with both viruses may occur.

Surveillance systems for hepatitis B and C differ widely across Europe and although EU notification rates of 3.5 cases per 100,000 (hepatitis B) and 7.8 cases per 100,000 population (hepatitis C) have been reported by the European Centre for Disease Prevention and Control, these figures are likely to be an underestimate of the true situation.

The highest rates of notification for hepatitis B are currently in northern European countries such as Poland, Sweden, the UK, Latvia and Ireland. For hepatitis C, the highest rates are in Scandinavia and other parts of northern or eastern Europe.

Effective hepatitis virus surveillance systems are now in place in most European countries and these have had a major impact on the healthcare burden of these conditions. Nevertheless, from the research highlighted in the Survey, hepatitis B and C continue to exert a heavy personal burden on affected individuals, with frequent physician visits, poor work performance and discrimination in the workplace commonly reported.

Effective hepatitis surveillance systems have reduced the healthcare burden of hepatitis B and C across Europe, but affected individuals continue to pay a heavy price.

GI diseases in children

The Survey of Digestive Health Across Europe evaluated a range of GI disorders that frequently affect children, including IBD, GORD, dyspepsia, *H. pylori* infection, coeliac disease and recurrent abdominal pain – all of which add to the burden of illness in Europe. The Survey reported that the incidence of many paediatric disorders was increasing in many countries, yet the impact of these conditions on the child’s social and psychological well-being is often overlooked.

Paediatric IBD is of particular concern, since up to 30% of cases of IBD begin in childhood, and studies suggest its prevalence is on the increase. Unfortunately, the Survey has emphasised the disparity between the quality of services provided to adults and that offered to children, and the lack of information on how children transition from paediatric to adult care.

Two welcome developments in the management of paediatric IBD are highlighted in the survey reports: joint publication by European Crohn’s and Colitis Organisation (ECCO) and the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) of the first paediatric specific guidelines for IBD patients and the initiation of the EUROKIDS registry.

The incidence of many childhood GI disorders is increasing in many countries, yet the impact of these conditions on the child’s social and psychological well-being is often overlooked.

GORD

2–10%
OF YOUNG
PEOPLE



INCIDENCE VARIES FROM
2 – 10% OF YOUNG
PEOPLE ACROSS EUROPE

MOST FREQUENT IN
INFANTS BETWEEN ONE
AND FOUR YEARS WITH
RISK FACTORS INCLUDING
LOW BIRTH WEIGHT AND
COW’S MILK ALLERGY

INFANTS
BETWEEN
1–4 YEARS

HELICOBACTER
PYLORI

HIGHEST INCIDENCE
AMONGST YOUNG
PEOPLE REPORTED
FROM EASTERN EUROPE
ALONG WITH PARTS OF
WESTERN EUROPE

PAEDIATRIC INFLAMMATORY BOWEL DISEASE, COELIAC DISEASE AND OESOPHAGITIS
ARE INCREASING IN MANY EUROPEAN COUNTRIES

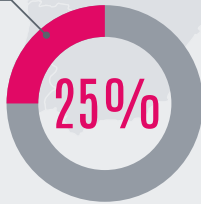


HIGH PREVALENCE
OF FUNCTIONAL
GI DISORDERS IN
CHILDREN

30%
OF ALL
IBD CASES

CHILDHOOD-
ONSET IBD
ACCOUNTS
FOR ABOUT
20 TO 30%
OF ALL CASES
OF IBD

DIAGNOSED
DURING
CHILDHOOD



UP TO ONE IN FOUR CASES
OF IBD PRESENT AND ARE
DIAGNOSED DURING CHILDHOOD
(UNDER THE AGE OF 16 YEARS)

PAEDIATRIC-ONSET
IBD INCREASE



A RECENT REVIEW OF THE INCIDENCE
AND PREVALENCE OF PAEDIATRIC-
ONSET IBD REPORTED A GENERAL
TREND FOR AN OVERALL INCREASE
OVER THE PAST FEW DECADES

HIGHEST INCIDENCE
CROHN’S DISEASE



HIGHEST REPORTED INCIDENCE OF
PAEDIATRIC CROHN’S DISEASE HAS
RECENTLY BEEN FROM SWEDEN,
HUNGARY AND NORWAY WITH LOWEST
INCIDENCE FROM POLAND

HIGHEST INCIDENCE
PAEDIATRIC
ULCERATIVE COLITIS



IN THE LAST DECADE THE HIGHEST
INCIDENCE OF PAEDIATRIC ULCERATIVE
COLITIS HAS BEEN REPORTED FROM
FRANCE, FINLAND AND HUNGARY



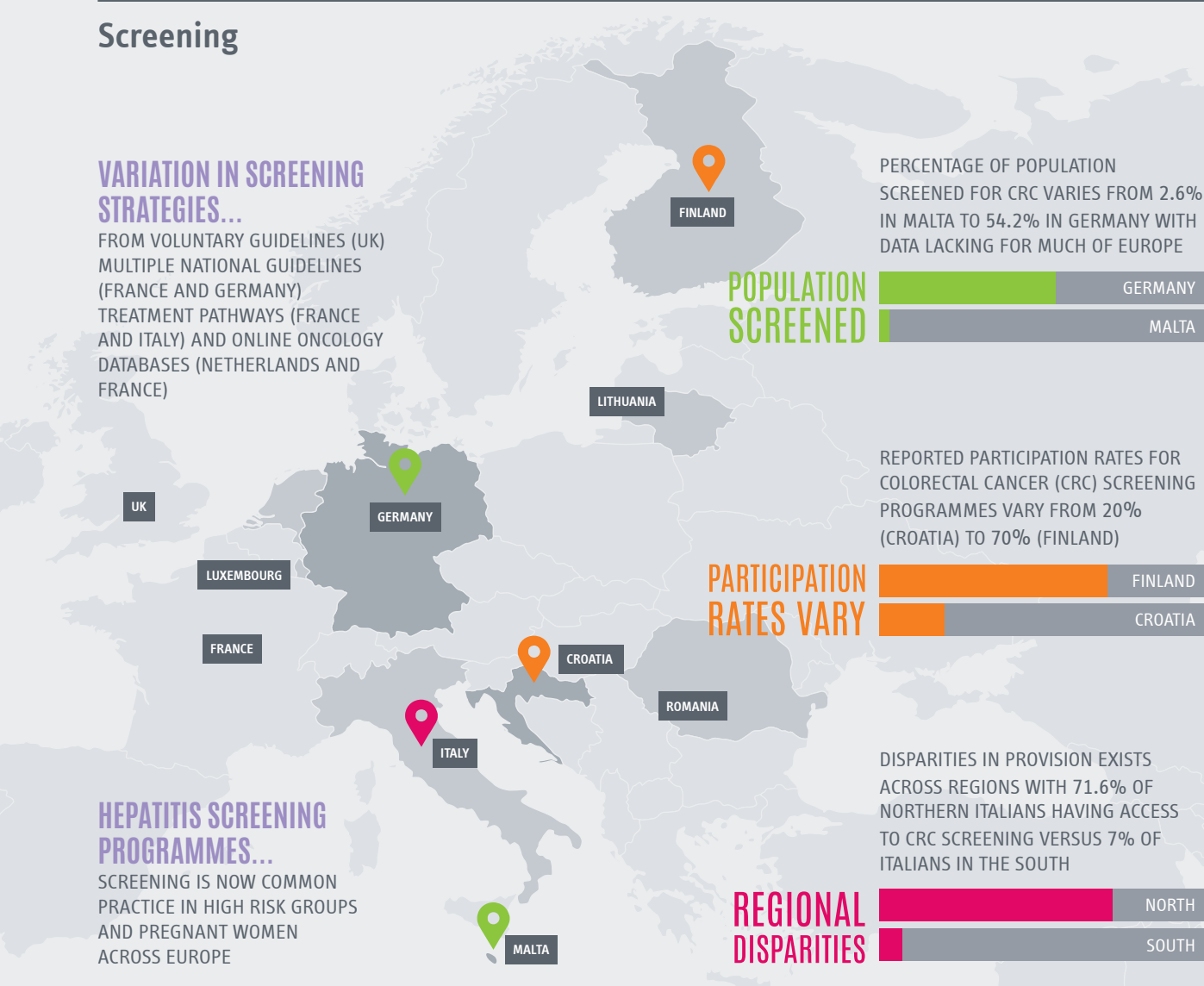
Screening

VARIATION IN SCREENING STRATEGIES...

FROM VOLUNTARY GUIDELINES (UK) MULTIPLE NATIONAL GUIDELINES (FRANCE AND GERMANY) TREATMENT PATHWAYS (FRANCE AND ITALY) AND ONLINE ONCOLOGY DATABASES (NETHERLANDS AND FRANCE)

HEPATITIS SCREENING PROGRAMMES...

SCREENING IS NOW COMMON PRACTICE IN HIGH RISK GROUPS AND PREGNANT WOMEN ACROSS EUROPE



POPULATION SCREENED

PERCENTAGE OF POPULATION SCREENED FOR CRC VARIES FROM 2.6% IN MALTA TO 54.2% IN GERMANY WITH DATA LACKING FOR MUCH OF EUROPE



PARTICIPATION RATES VARY

REPORTED PARTICIPATION RATES FOR COLORECTAL CANCER (CRC) SCREENING PROGRAMMES VARY FROM 20% (CROATIA) TO 70% (FINLAND)



REGIONAL DISPARITIES

DISPARITIES IN PROVISION EXISTS ACROSS REGIONS WITH 71.6% OF NORTHERN ITALIANS HAVING ACCESS TO CRC SCREENING VERSUS 7% OF ITALIANS IN THE SOUTH



NO HIGH RISK CONSENSUS

CURRENTLY NO EUROPE-WIDE CONSENSUS OVER SCREENING FOR HIGH-RISK GENETIC GROUPS

RISING DEMAND FOR SCREENING

DEMAND FOR SCREENING PREDICTED TO RISE WITH AGEING POPULATION

ILL EQUIPPED TO FUND MORE SERVICES



MUCH OF EUROPE WILL BE ILL EQUIPPED TO FUND AND RESOURCE MORE WIDESPREAD SCREENING PROGRAMMES AND SUBSEQUENT INCREASES IN ENDOSCOPIC AND CANCER SERVICES

Colorectal cancer (CRC) screening programmes are now well established in most European countries. The type of screening programme varies widely from population-based faecal occult blood testing to the targeted use of screening using flexible sigmoidoscopy or colonoscopy. Participation in population-wide CRC screening also varies widely across Europe. The Survey highlights the possibility that CRC screening programmes may potentially disadvantage other patient groups that require regular endoscopy services, pointing to significant variation in endoscopy services and capacity across Europe.

Screening for hepatitis B and C is also common practice across European regions, since early detection is critical for successful treatment and eradication of the disease. Screening now plays a crucial role in the fundamental function of hepatitis services, with most countries adopting routine screening for blood-borne viruses during pregnancy and some introducing additional screening programmes for high-risk groups. While these programmes may be heterogeneous, they have been credited with markedly reducing the burden of infectious hepatitis in Europe.

CRC screening programmes are well established in most European countries, although the types of programme and participation rates vary widely. Hepatitis B and C screening programmes have markedly reduced the burden of infectious hepatitis across Europe.

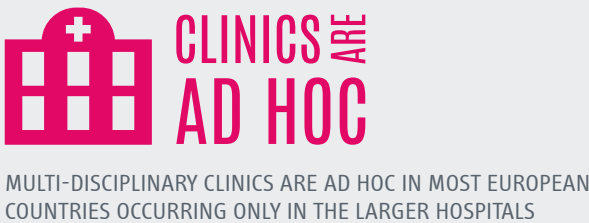
Training

High quality, standardised gastroenterology training is critical to future service delivery in Europe, however, significant heterogeneity remains in the delivery of education across the continent. Major differences in terms of the length of gastroenterology training, training methodologies used, and levels of supervision were identified by the Survey, with under-training reported in several key areas.

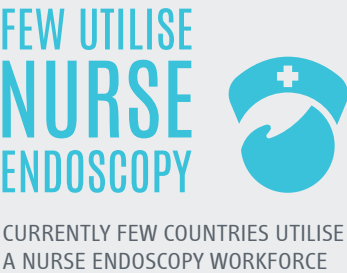
There is an absence of evidence from European countries on both the content and quality of postgraduate and undergraduate training in gastroenterology. The Survey identified a need to map different national curricula for postgraduate and undergraduate education within the European curriculum and to address the predicted future needs of the European population.

Both the knowledge-based examination developed by the European Board of Gastroenterology and Hepatology (EBGH) and the European training syllabus in paediatric gastroenterology developed by ESPGHAN are considered important initiatives to improve standards of training and reduce variability of practice across Europe and are highlighted in the Survey.

Significant heterogeneity in the delivery of gastroenterology education and training in key areas of GI medicine have been identified across the continent. This could potentially impact future service delivery in Europe.



A SURVEY OF 10 EUROPEAN COUNTRIES HIGHLIGHTED A LACK OF STANDARDISED TRAINING



The results of this survey have highlighted that there is generally poor reporting of the quality of life and economic impact of gastrointestinal disorders from the majority of European countries. Future research is required that will study incidence, prognosis and the public health burden of numerous GI conditions across Europe.

Specifically, research is needed to address the weak evidence base relating to the prevalence and public health burden of most liver diseases, the optimal tool for predicting the need for liver transplantation and the impact of minimal alcohol pricing levels.

Interested and specialist European groups need to address the absence of published work on the benefits of transitional clinics for inflammatory bowel disease and the psychological benefit for paediatric patients with IBD.

Accurate mapping of existing workforce data per head of population is a priority to ensure effective planning of future services and workforce training.

“

The Survey of Digestive Health Across Europe highlights some areas of good practice as well as showing many areas that require attention at both a national and European level. Our hope is that, ultimately, the Survey and the reports generated will help to improve care and health outcomes and reduce inequalities across the continent.

”

Michael Farthing, UEG President



Together we can advance
gastroenterological care

Starting the Conversation

Share your thoughts and comments on the situation across Europe and the priorities for improving service provision [@my_UEG](#) [#shapingGI](#)

To download the infographics or a summary of the Survey visit www.ueg.eu/research/activities

The full report can be found at:
ueg.sagepub.com/site/White_Book/White_Book.xhtml

