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## ECCO essential requirements for quality cancer care: Oesophageal and gastric cancer



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## ABSTRACT

**Background:** ECCO essential requirements for quality cancer care (ERQCC) are checklists and explanations of organisation and actions that are necessary to give high-quality care to patients who have a specific type of cancer. They are written by European experts representing all disciplines involved in cancer care. ERQCC papers give oncology teams, patients, policymakers and managers an overview of the elements needed in any healthcare system to provide high quality of care throughout the patient journey. References are made to clinical guidelines and other resources where appropriate, and the focus is on care in Europe.

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Europe  
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 Multidisciplinary  
 Organisation of care  
 Audit  
 Quality assurance  
 Patient-centred  
 Multidisciplinary team  
 Patient information  
 Health inequalities  
 Essential requirements  
 Guidelines  
 Healthcare system

### *Oesophageal and gastric: essential requirements for quality care:*

- Oesophageal and gastric (OG) cancers are a challenging tumour group with a poor prognosis and wide variation in outcomes among European countries. Increasing numbers of older people are contracting the diseases, and treatments and care pathways are becoming more complex in both curative and palliative settings.
- High-quality care can only be carried out in specialised OG cancer units or centres which have both a core multidisciplinary team and an extended team of allied professionals, and which are subject to quality and audit procedures. Such units or centres are far from universal in all European countries.
  - It is essential that, to meet European aspirations for comprehensive cancer control, healthcare organisations implement the essential requirements in this paper, paying particular attention to multidisciplinary and patient-centred pathways from diagnosis, to treatment, to survivorship.

**Conclusion:** Taken together, the information presented in this paper provides a comprehensive description of the essential requirements for establishing a high-quality OG cancer service. The ERQCC expert group is aware that it is not possible to propose a ‘one size fits all’ system for all countries, but urges that access to multidisciplinary units or centres must be guaranteed for all those with OG cancer.

## 1. Introduction: why we need quality frameworks

There has been a growing emphasis on driving up quality in cancer organisations, given that there is wide agreement that much care is not comprehensively accessible, not well coordinated and not based on current evidence. This is the starting point of a report by the US Institute of Medicine (IOM) in 2013 (Levit et al., 2013), which is blunt in describing a ‘crisis in cancer care delivery’, as the growing number of older people will mean rising cancer incidence and numbers of survivors, while there are pressures on workforces amid rising costs of care and complexity of treatments. The European Cancer Concord (ECC), a partnership of patients, advocates and cancer professionals, has also recognised major disparities in the quality of cancer management and in the degree of funding in Europe, launching a European Cancer Patient’s Bill of Rights, a patient charter that underpins equitable access to optimal cancer control, cancer care and research for Europe’s citizens (Højgaard et al., 2016).

An assessment of the quality of cancer care in Europe was made as part of the first EU Joint Action on Cancer, the European Partnership for Action Against Cancer (EPAAC, <http://www.epaac.eu>), which reported in 2014 that there are important variations in service delivery between and within countries, with repercussions in quality of care. Factors such as waiting times and provision of optimal treatment can explain about a third of the differences in cancer survival, while cancer plans, for example, a national cancer plan that promotes clinical guidelines, professional training and quality control measures, may be responsible for a quarter of the survival differences.

The EU Joint Action on Cancer Control (CANCON), which replaced EPAAC from 2014, also focused on quality of cancer care and in 2017 published the *European Guide on Quality Improvement in Comprehensive Cancer Control* (Albrecht et al., 2017). This recognises that many cancer patients are treated in general hospitals and not in comprehensive cancer centres (CCCs), and explores a model of ‘comprehensive cancer care networks’ that could reconcile expertise in existing healthcare systems given a lack of CCCs. Research also shows that multidisciplinary teams (MDTs) result in better clinical and organisational outcomes for patients (Prades et al., 2015).

Countries have been concentrating expertise for certain tumour types in such networks and in dedicated centres, or units, such as for childhood and rare cancers, and most CCCs have teams for the main cancer types. For common adult tumours, however, at the European level there has been widespread effort to establish universal, dedicated units only for breast cancer, following several European declarations that set a target of the year 2016 for care of all women and men with breast cancer to be delivered in specialist multidisciplinary centres. While this target has not been met (Cardoso et al., 2017), the view of ECCO’s essential requirements expert group is that the direction of travel is for all tumour types to adopt the principles of such dedicated care.

All patients with oesophageal and gastric cancer must have access to the care pathways and MDTs described in this document, and which are subject to same approach to auditing, quality assurance and accreditation of a ‘unit’ that is emerging in breast cancer and other common cancers such as colorectal.

## 2. Oesophageal and gastric (OG) cancer: key facts and challenges

### 2.1. Key facts

#### 2.1.1. What are OG cancers?

- Cancers of the oesophagus (food pipe) and the stomach (gastric) are grouped together because of common treatment and care features. In the oesophagus there are two main types: squamous cell carcinoma (SCC) and adenocarcinoma (AdC). In the stomach, the major type of cancer is AdC, either diffuse or intestinal. There are also tumours that straddle the oesophagogastric junction (OGJ), which are mostly AdCs. The molecular profiles of oesophageal and gastric tumours have been characterised: in the oesophagus, the molecular profile of SCC is distinct from that of distal oesophageal AdC, and the latter is similar to AdCs of the OGJ (Cancer Genome Atlas Research Network, 2017). For gastric cancer, 4 molecular subtypes have been identified (Cancer Genome Atlas Research Network, 2014). (Not included in this OG cancer group are less common carcinoma variants that affect the oesophagus and the stomach, mesenchymal tumours such as gastrointestinal stromal tumours (GIST), neuroendocrine neoplasms, and lymphomas.)
- Epidemiological studies tend to divide OG cancers into simply the oesophageal and gastric.

#### 2.1.2. Incidence and survival

Oesophageal cancer is the 19th most common cancer in Europe. Incidence in Europe was approximately 46,000 in the year 2012 (34,500 in 27 European Union countries), and there were approximately 39,500 deaths (30,000, EU), and the 5 year survival number (prevalence) was approximately 47,000 (38,000, EU) (Ferlay et al., 2013). It is rare in young people. There were wide differences in incidence and mortality among countries, with Western European countries including the UK, Netherlands, Ireland and Belgium with the highest rates, and the lowest in countries including Macedonia, Greece and Cyprus. European men have a much higher incidence of oesophageal cancer than women – about 4:1, although for junctional tumours that arise in the stomach the ratio is lower. AdC has increased greatly in incidence in the past few decades in developed countries – and has been among the most rapidly increasing of all cancers – while SCC rates have remained stable (SCC is by far the more common type in developing countries). More recently the incidence of AdC has tended to stabilise, and mortality rates in the EU of men have been declining.

Gastric cancer is the 5th most common cancer worldwide and the 7th most common in Europe. Incidence in Europe was about 140,000 in the year 2012 (81,000 in 27 European Union countries), and there were about 107,000 deaths (58,000, EU), and the 5 year survival number (prevalence) was about 193,000 (118,000, EU) (Ferlay et al., 2013). Patterns of incidence and mortality are very different in Europe to oesophageal cancer – Eastern European countries including Albania, Belarus, Macedonia and Russia have the highest rates, while Western European countries, including Sweden, Switzerland, France, Norway and the UK the lowest. More men than women have gastric cancer. Generally, incidence of non-cardia gastric cancers has fallen, but cardia cancers have increased in incidence. By far the most common form of gastric cancer is AdC.

The EURO CARE study (1999–2007) reported a mean 5 year survival for oesophageal cancer of 12.4% and an overall 5 year survival for gastric cancer of 25.1% (Anderson et al., 2015). The authors report that of the European regions, oesophageal cancer patients in Central Europe, particularly Belgium, had the best survival while the poorest were in Eastern Europe. For gastric cancer, Southern Europe had the best survival; Ireland and the UK, and Eastern Europe, the lowest.

### 2.1.3. Aetiology and risk factors

- Male gender and older age are risk factors for OG cancers. Smoking and alcohol play an important role for oesophageal cancer, and poor diet (including high salt intake) for gastric cancer. Obesity is particularly associated with a rising incidence of junctional cancers (with current research investigating obesity types and gender differences). Carcinogens are risk factors for gastric cancer in some occupations.
- The most important associated conditions for oesophageal cancer are gastro-oesophageal reflux disease (GORD) and Barrett's oesophagus, a premalignant condition for oesophageal AdC; and for gastric cancer, *Helicobacter pylori* infection (which the International Agency for Cancer Research identifies as a carcinogen for gastric cancer), and Epstein Barr virus.
- There is limited evidence for inherited links with oesophageal cancer, including familial clusters of Barrett's oesophagus and oesophageal AdC, and the association in the rare condition tylosis (hyperkeratosis palmaris et plantaris) with a high lifetime risk of SCC development. In gastric cancer there is familial clustering in 5–10% of cases (probably due to the interplay between genetic susceptibility and environmental factors such as *H. pylori* infection and diet), and 1%–3% are hereditary. Hereditary diffuse gastric cancer (HDGC), an autosomal-dominant cancer-susceptibility syndrome that affects the stomach, is mostly caused by germline mutations in the gene encoding E-cadherin (*CDH1*), leading to the occurrence of diffuse gastric cancer in young people (Guilford et al., 1998). Gastric cancer can also develop in the setting of other hereditary cancer syndromes (such as Lynch syndrome).

### 2.1.4. Prevention and screening

- At present, education about risk factors such as smoking, diet and obesity is the only primary prevention tool. Secondary prevention could include identifying and treating pre-cancerous conditions, such as Barrett's oesophagus, and *H. pylori*, but this is a complex area (*H. pylori*, for example, may be associated with lower incidence of oesophageal cancer). Chemoprevention, including taking aspirin, is among the interventions currently being studied.
- Screening is carried out for gastric cancer in Japan and South Korea, as there is high incidence in these countries (it is the most frequent cancer in Japan). There are no population level screening programmes elsewhere, but there are some guidelines to screen individuals who may be at higher risk (Yoon and Kim, 2015; Dinis-Ribeiro et al., 2012a).

### 2.1.5. Diagnosis and staging

- Symptoms that lead to a diagnosis of oesophageal cancer include difficulty in swallowing (dysphagia), lack of energy and strength (asthenia), gastrointestinal bleeding, weight loss, vomiting, indigestion, heart burn and chest pain. Common gastric cancer symptoms include dysphagia, asthenia, indigestion, vomiting, weight loss, early satisfaction of appetite and anaemia.
- Diagnosis of OG cancers is usually made from samples of the mucosa obtained by endoscopy and analysis by an experienced pathologist. High-quality staging is essential to determine optimal treatment, and includes endoscopic ultrasound to determine the extent and location of tumours, particularly of the oesophagus. Cross-sectional imaging with CT is used for detection of lymph node involvement and distant metastases. PET/CT is indicated in staging of oesophageal cancer and for some gastric cancers with increased sensitivity for distant metastases. Laparoscopy can additionally detect small volume peritoneal disease beyond the resolution of CT or PET/CT for both OG junctional and gastric cancers.
- The clinical and pathological staging of oesophageal, junctional and gastric cancers is determined by the TNM, 8th Edition. According to this classification, cancers crossing the OGJ and with their epicentre in the proximal 2 cm of the stomach are staged as oesophageal cancers. Cancers whose epicentre is more than 2 cm distal from the OGJ (in the proximal 2–5 cm of the stomach) are staged as gastric cancers even if the OGJ is involved. All tumours in the stomach that do not cross the OGJ are classified as gastric cancers (American Joint Committee on Cancer, 2016).

### 2.1.6. Treatment

- Endoscopic therapy, including mucosal resection/submucosal dissection, is the preferred surgical approach in both very early, superficial oesophageal and gastric cancers (T1a). Surgical resection is carried out for early stage cancers not suitable for endoscopic resection and can be curative. Radical and often complex surgical techniques, including lymph node procedures, are carried out in more advanced, operable OG cancers, together with various perioperative chemotherapy and chemoradiotherapy regimens. Not all patients are willing or able to undergo surgery because of co-morbidity but can still receive chemoradiotherapy or radiotherapy.
- In advanced/metastatic inoperable oesophageal cancer, care comprises palliative chemotherapy, and radiotherapy in some cases. In advanced/metastatic inoperable gastric cancer, standard treatment is chemotherapy. Trastuzumab is mandatory for HER2 positive gastric cancer (which is 10%–15% of cases) and an anti-VEGFR-2 monoclonal antibody (ramucirumab) can be considered for second line alone or with chemotherapy. Immunotherapy checkpoint inhibitors (PD-1/PD-L1, CTLA4) have also shown efficacy in early studies in advanced OG cancer. Nutritional support and palliative care should be considered from the beginning of the treatment for all patients.

## 2.2. Challenges in care of OG cancers

### 2.2.1. Inequalities

- Eastern Europe has the worst survival for OG cancers, in line with most tumour types, which is a major concern. But there also appear to be substantial variations in survival among Western European countries – for oesophageal cancer, the 5 year relative survival rate was 8.9% in Denmark and 16.2% in Germany; for gastric cancer 16% in Denmark and 32.4% in Italy (figures from EURO CARE-5, 1999–2007) (De Angelis et al., 2014). The reasons could lie in a number of factors, such as use of multimodal therapies, surgical approach and post-operative care, but a lack of comprehensive data

from cancer registries is also likely to be a current challenge particularly for data on epidemiology and stage at presentation (Messager et al., 2016a).

- A majority of cases are among older people – for example, in the UK 56% of cases at diagnosis are in those over 70. There is evidence that older cancer patients are undertreated (Quaglia et al., 2009) and are also underrepresented in clinical trials (Scher and Hurria, 2012). Providing the standard of care to older people in all cancers is important and is particularly challenging in these cancers, because of the numbers of patients frequently with several comorbidities to manage, and consistent partnership with geriatric specialists can be needed.

### 2.2.2. Diagnosis and staging

- Treatment of symptoms that appear to be common complaints such as dyspepsia can delay diagnosis. Many patients with OG cancers are diagnosed when their disease is at an advanced stage, owing to this vagueness of, or even lack of, symptoms, and lack of understanding symptoms and their relevance to possible underlying cancer. Overall, about 60% of people with OG cancers are not eligible for curative treatment owing to late presentation or co-morbidities. Raising public awareness of symptoms including persistent heartburn and dysphagia may be effective, such as with the UK Be Clear on OG Cancer campaign in which TV and ‘roadshows’ targeted men and women over 50 from lower socioeconomic groups, encouraging them to visit their GP (<http://www.cancerresearchuk.org/health-professional/awareness-and-prevention/be-clear-on-cancer/oesophago-gastric-cancers-campaign>). The briefings and campaign materials are on the site. A supporting study also showed wide variation in referral rates by GPs for gastroscopy and a higher risk of poorer outcomes among those with lower rates (Shawihdi et al., 2014).
- OG cancers are particularly complex to stage and assess for treatment, and there are variations in investigations and referral strategies among European countries that can affect outcomes.

### 2.2.3. Treatment

- Centralised multidisciplinary expertise is essential to determine the best holistic treatment course and to implement the latest research findings. Fragmentation in services and expertise, still apparent in many countries, must be eliminated.
- Treatment of OG cancer with curative intent has been clearly shown to have a volume-outcome effect, so centres must have a sufficient number of cases to ensure and maintain expertise.
- OG cancer treatment includes surgical options that are highly demanding and must be carried out in specialised centres with experienced surgeons and anaesthesiologists. These centres should include emergency presentations. Decision making about treatment often involves a complex assessment of the balance between benefits and complications, not least the decision about whether to carry out curative or palliative care.
- Surgeons undertaking operations for OG cancers should treat all types – oesophageal, junctional and gastric – as there are common principles to ensure development and maintenance of expertise.
- Specialist care during and after surgical treatment is critical to reducing post-operative mortality.
- Assessment of and support for nutritional status is needed for all patients as many patients are malnourished.
- Low numbers of operable cases means that the concept of a ‘high volume’ surgical centre can involve far fewer cases than more common operable cancers, such as colorectal. Inoperable cases, however, also require specialist interventions and treatment. It is a challenge for health services to consistently provide a full multidisciplinary team for all cases.
- Overall, patient care pathways for OG cancers are among the most

complex to organise and manage, given the need for high quality local diagnostic and palliative care services and their integration with specialist centres.

### 2.2.4. Palliative treatment and supportive care

- It is essential that patients not undergoing curative treatment receive palliative and supportive care as part of their multidisciplinary treatment. Palliative care is often lacking in multidisciplinary teams but essential to quality of life.
- Patient reported outcomes and quality of life are crucial in OG cancers but are often poorly addressed, particularly in clinical trials.
- The number of cancer survivors is rising, and some survivors suffer for many years from ongoing conditions, such as digestive disorders, that result from the primary treatment of their cancer. Specialist supportive care for a growing population of survivors is becoming a major issue.

### 2.2.5. Clinical research

The main challenges in clinical research for OG cancers in Europe are the relative low incidence compared with Asia, variability in multidisciplinary management and treatment, and lack of centralisation of cancer care, which all contribute to the limited access for many patients to clinical trials. Practice-changing research for OG cancer has been conducted through strong national groups, but conducting international clinical trials remains a challenge. Close collaboration among surgeons, oncologists, pathologists and biologists is needed to generate innovative translational research that will direct better clinical trials.

### 2.2.6. Patient advocacy

OG cancers do not yet have many national patient groups. They can play a vital role in service improvement strategies, in providing information, and in the quality of life of patients, and require support and funding.

## 3. Organisation of care

Essential requirements for the organisation of OG cancer care encompass:

- Cancer care pathways
- Timelines of care
- Minimum case volumes
- Multidisciplinary teamworking among core and extended groups of professionals, in a dedicated centre or unit
- Audit, performance measurement, quality assurance of outcomes and care
- Professional education, enrolment in clinical trials and delivery of patient information.

These topics are outlined in the following sections, with reference to national and European resources and clinical guidelines, where appropriate.

### 3.1. Care pathways and timelines

- Care for OG cancer patients must be organised in care pathways that chart the patient’s journey from their perspective rather than that of the healthcare system. The European Pathway Association defines a care pathway as “a complex intervention for the mutual decision making and organisation of care processes for a well-defined group of patients during a well-defined period”. This broad definition covers terms such as clinical, critical, integrated and patient pathways that are also often used. See <http://e-p-a.org/care-pathways>.
- Pathways should incorporate current evidence set out in national and European guidelines. An example of a pathway for OG cancers is

from the Cancer Council, Victoria, Australia (Cancer Council Victoria, 2018).

- Primary care practitioners are the usual referrers of those with suspected OG cancers and need timely access to hospital specialists. In England and Wales, the maximum time for an appointment to check suspected symptoms of all cancers is 2 weeks (NICE guidance, UK). Other countries have shorter targets: in the Netherlands, the maximum time for an appointment when a malignancy is suspected is 1 week. The ERQCC expert group strongly recommends that countries ensure that waiting times are below these times, as is the case in several European countries that make urgent referrals within 48 h. There must be documented local referral policies for diagnosis of OG cancers, agreed between all levels of service including primary care.
- Times to report a diagnosis of OG cancer and the opportunity to start treatment are crucial to the wellbeing of patients to avoid as much anxiety as possible. Guidelines in the Netherlands (and similarly in Germany), for example, state that the maximum time for diagnostic and staging procedures is 3 weeks, and the maximum time from first appointment to first treatment is 6 weeks.
- Treatment planning for all patients with OG cancer must be undertaken by a multidisciplinary team (see below).
- After a diagnosis, it must be clear to the patient which professional is responsible for each step in their multidisciplinary treatment pathways and who is following the patient during the journey (usually called a case manager or patient navigator). In many countries, case managers during the main stages of treatment are cancer nurses (European Partnership for Action Against Cancer, 2018), with some being specialists in OG cancers. There must also be a medical professional responsible for coordinating treatment modalities and specialties. This is usually a surgeon or medical/clinical oncologist, depending on local agreements and the stage of the disease.
- Some patients with OG cancers present as emergencies. While it is preferable for these patients to be treated by the OG team from the start, this is often not possible. Care must be transferred to the OG team straight after the emergency procedure. In the UK, the survival rate at 1 year for emergency admissions is only about half that of other routes to diagnosis (Coupland et al., 2007).
- Rehabilitation and survivorship are major issues in OG cancers. Regular follow-up may detect recurrence, though there is no evidence that it improves survival outcomes (National Institute for Health and Care Excellence, 2018; Baiocchi et al., 2016). However, OG cancer treatments, both acutely and in the longer term, create significant symptoms which impair quality of life. Patients with OG cancer are living longer and these treatment related side-effects can be lifelong. It is therefore essential for units and centres undertaking OG cancer treatment to ensure there is an easily accessible multidisciplinary service to manage these problems.

### 3.2. OG centres/units: requirements

- It is essential for all patients to be treated in a multidisciplinary centre; that members of the multidisciplinary team see a certain annual number of cases; and that members of the core team dedicate significant time to treating patients with OG cancer, although requirements vary according to the various disciplines in the team. There is good evidence that countries that have centralised OG cancer services and/or specify a minimum number of cases achieve better outcomes, especially in post-operative mortality (Glatz and Höppner, 2017). One study, looking at data on oesophageal surgery in Sweden, found that a surgeon's volume, rather than hospital volume, is the key variable (Derogar et al., 2013). In gastric surgery, guidelines and studies show that the D2 lymphadenectomy procedure should be carried out only in high volume centres (Smyth et al., 2016; Songun et al., 2010).
- Supporting evidence for guidance from NICE notes that there has

been a recommendation in the UK NHS for the minimum size of catchment population for a specialist OG centre to be 1 million, and adds that units now tend to cover populations of 2 million or more, following centralisation initiatives. NICE also says it is difficult to assess surgeon volume given a requirement for round the clock specialist surgeon cover and operations increasingly being carried out by two consultants. The draft guidance lists studies on organisation of surgical services and hospital volume, although most are of low or moderate quality (National Institute for Health and Care Excellence, 2018). The Association of Upper Gastrointestinal Surgeons of Great Britain and Ireland has said that an ideal OG unit would consist of 4–6 surgeons each carrying out a minimum of 15–20 OG resections a year serving a population of 1–2 million (Association of Upper Gastrointestinal Surgeons of Great Britain and Ireland, 2010). The German Cancer Society requires 30 gastric resections per year by two dedicated surgeons to qualify for certification as a gastric cancer centre (German Cancer Society, 2016).

- Based on the existing evidence, the ERQCC expert group recommends that a specialist multidisciplinary team at a centre or network should manage and consult on about 200 new OG cases each year (the total being both curative and palliative treatments, and those referred but treated elsewhere) although it is recognised that in some countries both incidence and geography can influence case volume and a lower total would be more appropriate.
- All OG units must have a follow-up programme in place in accordance with guidelines.

### 3.3. The multidisciplinary team

Treatment strategies for all patients must be decided on, planned and delivered as a result of consensus among a core multidisciplinary team (MDT) that comprises the most appropriate members for the particular diagnosis and stage of cancer, patient characteristics and preferences, and with input from the extended community of professionals. The heart of this decision making process is normally a weekly or more frequent MDT meeting where patients are discussed with the objective of balancing the recommendations of clinical guidelines with the 'reality' of the individual patient. Currently, there is variability in OG MDTs across Europe both in the constitution of the teams and the frequency of meetings (Messenger et al., 2016a).

The standard of care for patients with OG cancer includes a core MDT of dedicated health professionals from the following disciplines:

- Gastroenterology/endoscopy
- Pathology
- Radiology/interventional radiology
- Surgery
- Nuclear medicine
- Radiation oncology
- Medical oncology
- Nursing
- Nutrition
- Palliative care.

This core MDT must discuss:

- All new patients after diagnosis and staging to decide on an optimal treatment plan whether for curative or palliative intent
- Patients after major treatment to decide on further treatment (such as adjuvant chemotherapy) and follow-up
- Patients with a recurrence during follow-up to decide on optimal treatment
- Patients for whom changes to treatment programmes are indicated and have multidisciplinary relevance and/or may require deviations from clinical practice guidelines.

Healthcare professionals from the following disciplines comprise the extended MDT. They do not need to attend every MDT meeting but have essential roles for aspects of patient care and their expertise must be included when necessary:

- Anaesthesia/intensive care
- Geriatric oncology
- Oncology pharmacy
- Psycho-oncology
- Physiotherapy
- Rehabilitation and survivorship.

Guidelines from ESMO emphasise that nutritional counselling is essential for localised and advanced cases; that specialised supportive and palliative care is available for advanced cases; and survivors have access to gastrointestinal specialists throughout their follow-up (Smyth et al., 2016). To ensure timely and adequate preoperative workup and preparation, anaesthesia/intensive care should be involved as soon as possible after the decision for surgical treatment.

### 3.4. Disciplines within the core MDT

#### 3.4.1. Gastroenterology/endoscopy

Gastroenterologists are usually the first physicians who assess a patient with possible OG cancer. In some countries gastroenterologists also carry out medical oncology treatments.

Upper gastrointestinal endoscopy is the principal investigation, with biopsy for histological confirmation of diagnosis of OG cancer. Endoscopy is carried out by gastroenterologists, surgeons, nurse endoscopists and radiologists, depending on country/locality.

Endoscopic diagnosis can be supplemented by endoscopic ultrasound as part of interventional staging.

Interventional endoscopy is also part of the management of patients with OG cancer. In early stage disease, endoscopic resection is performed (endoscopic mucosal resection, EMR; endoscopic submucosal dissection, ESD). This may be supplemented by endoscopic-directed mucosal ablation techniques such as radiofrequency ablation. Endoscopic techniques also have a role in symptomatic palliation including stent placement or laser therapy for stenosing cancers.

#### Essential requirements

- A gastroenterologist/endoscopist must be trained and accredited in diagnostic upper GI endoscopy (Beg et al., 2017; Bisschops et al., 2016; Dinis-Ribeiro et al., 2012b; Weusten et al., 2017; Spaander et al., 2016). Endoscopists performing interventional endoscopy and endoscopic ultrasound must have a sufficient practice as specified by country regulations (e.g., according to number of procedures such as EMR/ESD performed a year, completeness of procedures, FNA/core needle biopsies).
- High-definition video endoscopy must be used for diagnosis and treatment.
- Facilities for endoscopic palliation of malignant dysphagia must be available within 24 h of presentation.
- The endoscopy service must be subject to quality assurance with appropriate regular audit.
- In countries where systemic treatment of gastrointestinal cancer is carried out by gastroenterologists, they must have a qualification and expertise in the systemic treatment of gastric cancer and the management of side-effects (e.g. as demonstrated by a certain number of chemotherapeutic cycles and targeted agents given each year). They must also follow up after surgery to make sure that adjuvant treatment, for example, is applied when indicated.

#### 3.4.2. Pathology

Pathology, including molecular pathology, is playing an

increasingly critical role in the diagnosis of OG cancer. The role of the pathologist is to conduct a detailed study of the tumour based on the sample/specimen received for analysis and to prepare a pathology report for discussion at the MDT.

#### Essential requirements

- Pathologists must have expertise in reporting on OG cancer pre-operative biopsies, EMR/ESD specimens and surgical specimens. They must know recently published guidelines and reviews on pathological reporting and their reports must contain a list of items as recommended by professional organisations and internationally recognised classifications used for histopathological diagnosis (Bosman et al., 2010; Lauren, 1965). The use of structured (or synoptic) reports is strongly encouraged; see examples from the Royal College of Pathology in the UK (Royal Society of Pathologists, 2007a, 2007b).
- Second opinion must be sought internally for differential diagnosis between precursor lesions (dysplasia) and invasive cancer; discrepancy between the clinical and pathological diagnosis; and for rare tumours in which pathologists have little experience (such as early intra-epithelial lesions of HDGC). External second opinion must be made to national or international experts in certain cases.
- With the increasing importance of molecular data in therapeutic decisions (Baraniskin et al., 2017), access to an accredited molecular pathology laboratory must be guaranteed, although it may not be on site. For OG adenocarcinomas the evaluation of HER2 status is part of standard diagnostics; MSI is recommended only for stage IV. PD-L1 expression and detection of EBV in tissue (EBER) are not recommended yet in routine use. Search for *CDH1* mutations is mandatory for HDGC (van der Post et al., 2015).

#### 3.4.3. Radiology/interventional radiology

OG cancers are complex diseases that require multimodal imaging to assess and stage. Imaging the oesophagus and stomach is challenging because they are flexible tube/hollow organs, not optimally distensible and surrounded by other vital organs. Conventional radiography and barium swallow with fluoroscopy is not indicated as part of the assessment of OG cancer. Multidetector CT (MDCT) is the modality of choice to assess stage (Ba-Ssalamah et al., 2009, 2003, 2011). MRI is not routinely used in the preoperative evaluation of these cancers, but is useful in the diagnostic work up of liver lesions.

Interventional radiology can be required for diagnosis, particularly of recurrent disease, and therapy in OG cancer, particularly in the management of postoperative complications and relief of symptoms in recurrent disease (Tamandl et al., 2016a, 2016c, 2016b).

#### Essential requirements

- Radiologists must have expertise in gastrointestinal imaging.
- OG cancer staging is based mainly on computed tomography (CT) findings, and radiologists must have knowledge of CT protocols for assessment of primary tumours, nodal spread, intraperitoneal disease and metastatic spread.
- Radiologists must also know how to assess response after neoadjuvant cancer therapy. This is an evolving area where integration of radiologic, clinical and endoscopic data is mandatory.
- Radiologists must know when to refer a patient to nuclear medicine for PET/CT. State-of-the-art CT, liver MR imaging and PET/CT, including adequate reporting, must be available.
- Interventional radiologists must be competent in image guided biopsy techniques and therapeutic interventions such as stent placement and have competence in intravascular techniques (or be able to refer to a colleague).

#### 3.4.4. Nuclear medicine

Nuclear medicine plays a role in the management of oesophageal and OGJ cancer patients, and in some gastric cancer patients (Boellaard

et al., 2015; Jadvar et al., 2017).

There is evidence of the efficacy of  $^{18}\text{F}$  FDG PET/CT in selected clinical indications:

- Initial staging of oesophageal cancer, stages IB to IIIC: based on ESMO guidelines,  $^{18}\text{F}$  FDG PET/CT should be carried out in patients who are candidates for oesophagectomy (Lordick et al., 2016). Evidence shows  $^{18}\text{F}$  FDG PET/CT has a high accuracy for N and M staging, especially in identifying otherwise undetected distant metastases, and so is key in decision-making (i.e. finding distant metastases may prevent patients from undergoing futile surgery)
- Prediction of response: based on ESMO guidelines, tumour response to chemotherapy may be predicted early in oesophageal and OGJ AdC
- Prognostic value, both at initial diagnosis and during early response monitoring
- Early detection of relapse, in patients with increased tumour markers and/or inconclusive CT or MR.

Other clinical situations with limited evidence, but with ongoing research and promising preliminary results are:

- Radiation oncology treatment planning, defining the gross tumour volume (GTV) and evaluating candidates with probable oligometastatic disease before stereotactic body radiotherapy (SBRT)
- Guiding biopsies with the information supplied by  $^{18}\text{F}$  FDG PET/CT, improving the probability of successful extraction of diagnostic tissue.

The role of the nuclear medicine physician is to oversee all aspects of PET/CT for patients who require this procedure, including indications, multidisciplinary algorithms and management protocols.

#### Essential requirements

- PET/CT and SPECT/CT must be available and must be managed by nuclear medicine physicians with the appropriate expertise.
- Nuclear medicine must be able to perform daily verification protocols and to react accordingly. Quality-assurance protocols must be in place. An option for ensuring the high quality of PET/CT scanners is provided by the European Association of Nuclear medicine (EANM) through EARL accreditation.

#### 3.4.5. Surgery

Surgery is a component of curative treatment of OG cancer in about 25% of patients (NHS, 2016). The majority of these patients require multidisciplinary treatment usually combining surgery and perioperative chemotherapy or preoperative chemoradiotherapy, although surgery only is appropriate for selected patients with early stage disease not suitable for endoscopic therapies (Allum et al., 2011). Surgery also has a role in the palliative setting to relieve local symptoms that cannot be treated endoscopically.

The role of the surgeon is to assess suitability for surgery in terms of the extent of the cancer, including laparoscopy for staging, and also patient fitness in the context of the multidisciplinary decision; undertake the surgical procedure; and be responsible for perioperative care. Minimally invasive techniques are becoming part of standard practice and should be introduced following structured and proctored training of the surgical team.

#### Essential requirements

- Staging laparoscopy must be undertaken by a specialist surgeon who regularly performs OG cancer surgery.
- OG resection surgery must only be carried out in specialist centres by teams of appropriately trained surgeons with audited outcomes. There must be at least two experienced surgeons per unit who dedicate a significant amount of their time to OG cancer. The ERQCC expert group recommends that surgeons should perform both oesophageal and gastric resections. Centres must have

sufficient numbers to ensure maintenance of expertise.

- OG surgeons at a specialist centre must provide a 24/7 on-call service including emergency service and advice to local hospitals for malignant OG disease as well as spontaneous and iatrogenic perforation, including benign pathology.
- Surgeons must ensure that perioperative care for patients undergoing OG resection are provided by specialist teams of nurses (both in the operating theatre and on the wards) and anaesthetists/intensivists with access to intensive and critical care facilities.

#### 3.4.6. Radiation oncology

Radiotherapy is often used before surgery in oesophageal cancer to facilitate curative resection with clear margins and to reduce the risk of local recurrence, in particular in SCC. Preoperative chemoradiation in oesophageal cancer has been shown to increase disease free and overall survival. It can be selectively used after surgery in a small minority of patients with high risk factors for local recurrence who did not receive preoperative radiotherapy. SCC of the oesophagus can also be treated with chemoradiation alone without surgery. Decision-making is multidisciplinary and takes many factors into account (Lordick et al., 2016).

The role of radiotherapy in the treatment of gastric cancer is under study (Smyth et al., 2016).

The role of the radiation oncologist is to determine the volume to be irradiated based on the clinical staging of the primary tumour. Multimodal imaging including a CT in the treatment position is used to delineate the target volume. Radiation oncologists are responsible for the dose fractionation prescription in keeping with national and international guidelines.

Radio(chemo)therapy can help control AdCs in people who are not healthy enough for surgery or to ease (palliate) symptoms in people with advanced cancer that has caused severe dysphagia, bleeding or pain. Radiation oncologists are responsible for patients' ongoing care and wellbeing according to these clinical situations.

#### Essential requirements

- Access to radiotherapy must be provided in the centre.
- The radiotherapy centre must have agreed protocols for radiotherapy and concurrent chemoradiotherapy for OG cancer based on international guidelines. The image guidance policy and quality assurance guidelines must be clearly described and documented. External quality assurance audits are highly recommended.
- Access to 3D conformal radiotherapy and intensity modulated radiation therapy (IMRT), where clinically indicated, must be available and delivered according to clearly defined protocols. Radiation oncologists must be responsible for follow-up and management of late toxicity and survivorship issues. Protocols must be in place for the management of late toxicity including digestive, pulmonary and cardiac problems.

#### 3.4.7. Medical oncology

Medical oncology plays an important role in the management of OG cancer patients, and specifically of patients with locally advanced and metastatic disease (stages IB–IV). In these situations, the medical oncologist is the lead oncology specialist. The role of the medical oncologist is to:

- Coordinate all aspects of multimodal drug treatment, which may include coordination of clinical and molecular diagnostics, and indication setting and distribution of treatment with systemic therapies (such as perioperative, adjuvant and palliative chemotherapy, monoclonal antibodies, and, potentially in the future, signal-transduction inhibitors and immunotherapies)
- Initiate and coordinate symptom-related management in cooperation with specialists who manage tumour or disease-related symptoms (palliative and symptomatic treatment, including nutritional support), and rehabilitation and survivorship
- Play a lead position in clinical trial design for locally advanced and metastatic OG cancers.

### Essential requirements

- Medical oncologists treating OG cancer must have in-depth understanding of the prognostic and predictive clinical and molecular factors that contribute to indication setting, treatment intensity and duration of drug therapies. These factors must be considered with clinical goals and other, non-disease related factors and patient preferences. Medical oncology for OG cancer is increasingly complex, as evidenced in the latest clinical guidelines and reports (Lordick et al., 2016; Smyth et al., 2016, 2017; Ajani et al., 2017).
- Medical oncologists must have in-depth knowledge of the interaction of cancer-specific treatments with other conditions (such as comorbidities and their management). This includes supportive treatment for management of pain, weight loss, gastrointestinal symptoms and side-effects of systemic therapy.

#### 3.4.8. Nutrition/diet

Nutritional and metabolic problems are frequent in patients with OG cancer; aggressive curative surgery and perioperative multimodal oncologic care can induce a progressive nutritional decline. Indications for nutritional therapy are prevention or treatment of malnutrition and catabolism. Nutrition therapy may be indicated even in patients without obvious disease-related undernutrition, if it is anticipated that the patient will be unable to eat or cannot maintain appropriate oral intake for a long period perioperatively. In this case, the surgeon should place a naso-jejunal tube or needle catheter jejunostomy intraoperatively. Diets supplemented with specific nutrients can be used perioperatively to reduce the inflammatory response and to enhance the immune function.

Physical activity is associated with improvement of aerobic capacity, increasing anabolism and muscle strength, enhancing health-related quality of life, and anxiety reduction.

The nutritionist or dietitian is an essential member of the core MDT to manage these interventions, as set out in guidelines (Weimann et al., 2017; Arends et al., 2017).

### Essential requirements

- Nutritionists must carry out systematic nutrition risk screening at the time of diagnosis of OG cancer, including assessment of body composition (fat free mass, visceral fat), dietary intake and physical activity.
- Nutritionists must prepare a nutrition intervention plan (in case of inadequate food intake, oral nutritional supplements, enteral or parenteral nutrition should be used)
- Nutritionists must support the tolerability of therapeutic measures.
- Counselling with good communication skills is necessary to ensure compliance with plans.
- Regular follow-up of body weight and BMI must be carried out.

#### 3.4.9. Nursing

The OG pathway is complex and nurses are in a key position to identify and address the holistic needs of the individual from diagnosis through to recovery. Through strategies such as tailored support, timely information and symptom management nurses can alleviate distress and promote supported self-management.

Nurses can refer patients to services such as patient support groups, clinical psychology and welfare advisors to ensure the patient's needs are optimised and addressed.

Extended nursing roles for cancer nurses (known for example as clinical nurse specialists or advanced nurse practitioners) are now common in some countries and include performing endoscopy, delivering systemic treatments and running survivorship clinics (NHS National Cancer Action Team, 2010; Royal College of Nursing, 2009). See also the Recognising European Cancer Nursing (RECaN) project (<http://www.ecco-og.eu/Policy/RECaN>).

### Essential requirements

- Nurses working in OG centres must have insight into each patient's experience of their disease, treatment and side-effects, and must promote a culture of shared decision-making and patient involvement throughout the cancer continuum (from diagnosis through to recovery). They must act in the best interest of the patient and those important to them to help coordinate diagnosis, treatment and aftercare, acting as a key worker (or case manager) where appropriate. In some circumstances it may be more appropriate for the palliative care nurse to assume this role but at all times the patient should have clarity on who their single point of contact is.
- Nurses must focus on the timely, holistic assessment and management of the patient and represent their needs at the MDT where appropriate. Nurses must ensure systematic screening throughout the disease trajectory to uncover physical symptoms such as pain, psychosocial distress, impairment of physical functioning, malnutrition and frailty.
- Nurses must be trained in perioperative care for patients undergoing all forms of OG surgery and procedures.
- In collaboration with the MDT, nurses must agree on the optimal methods, frequency and duration of follow-up for people following treatment for OG cancer.

#### 3.4.10. Palliative care

About 60% of patients with OG cancer have incurable disease and need palliative care in conjunction with cancer treatments to manage distressing clinical complications and symptoms, and improve their quality of life and that of their families (Temel et al., 2010; Hui et al., 2015; Quill and Abernethy, 2013). Palliative care, as defined by the World Health Organization, applies not only at end of life but throughout cancer care (<http://www.who.int/cancer/palliative/definition>).

All professionals working with OG cancer patients should have knowledge of palliative care, but the ERQCC expert group considers that in this patient group specialists must be integrated into the core team.

The role of the palliative specialist is to:

- Manage palliative care and make recommendations to other specialists about symptom control and other conditions
- Identify patients who need palliative care through the systematic assessment of distressing physical, psychosocial and spiritual problems
- Treat disease and treatment-related symptoms and offer psychosocial and spiritual care
- Incorporate support for family members
- Provide early integrated palliative care in conjunction with cancer specific treatments
- Provide end-of-life care and support decision making, working with primary care palliative care providers (Gallais S  r  zal et al., 2016).

### Essential requirements

- All OG cancer patients with severe symptoms or suffering, or patients with metastatic or locally advanced disease, must be introduced to a specialist palliative care team, irrespective of the cancer-specific treatment plan.
- The palliative care team must include palliative care physicians and specialist nurses, working with an extended team of social workers, chaplains, psychotherapists, physiotherapists, occupational therapists, dieticians, pain specialists and psycho-oncologists.
- The specialised palliative care team must have good knowledge of cancer disease and cancer treatments including adverse effects of treatment, disorders of digestive physiology, cachexia and malnutrition, and rehabilitation needs of patients, to be able to offer



holistic care in collaboration with other professionals.

- To ensure the continuity of care at home, the palliative care team must work with primary care providers.
- Palliative care specialists and oncologists must aspire to meet the standards of the ESMO Designated Centres of Integrated Oncology & Palliative Care (<http://www.esmo.org/Patients/Designated-Centres-of-Integrated-Oncology-and-Palliative-Care>).

### 3.5. Disciplines in the extended MDT

#### 3.5.1. Anaesthesia/intensive care

Anaesthesiologists have key roles in the management of patients with OG cancer. These include:

- Surgical risk assessment
- Preoperative optimisation of co-existing medical conditions
- Perioperative clinical pathway management (including intraoperative care)
- Postoperative management in intensive/critical care facilities
- Acute and chronic pain management.

Enhanced recovery pathway guidelines for oesophageal and gastric surgery have been published and should be implemented to facilitate perioperative care (Feldheiser et al., 2016).

Surgical centres must have the necessary anaesthetic and critical care expertise and infrastructure not only to manage elective OG cancer surgery but also to provide the often complex support for postoperative complications in high-risk patients, which may include extended cardiovascular support and invasive ventilator support (e.g. oscillating ventilation and ECMO).

#### Essential requirements

- Patients undergoing OG cancer surgery must have appropriate preoperative assessment led by anaesthesiologists.
- Anaesthesiologists undertaking OG cancer surgery must have adequate experience in thoracic surgery anaesthesia including one-lung ventilation, the use of double-lumen endotracheal tubes and bronchial blockers and awake fibre optic bronchoscope intubation; epidural analgesia and thoracic-abdominal regional techniques; and invasive intraoperative haemodynamic monitoring.
- Postoperative care must be undertaken in dedicated intensive/critical care facilities.
- The standard of care for OG cancer surgery includes enhanced recovery programmes, which are recommended for all OG centres.
- Pain control services led by anaesthesiologists must be available in centres providing care for patients with OG cancer.

#### 3.5.2. Geriatric oncology

Older patients are heterogeneous, with large variations in remaining life expectancy and vulnerability, and age alone should not guide the treatment of OG cancer. Comorbidity, which is frequently present, is an important prognostic factor (Koppert et al., 2012). In patients with SCC, many patients suffer from chronic obstructive pulmonary disease (COPD), while patients with AdC often have cardiopulmonary comorbidities. In addition, weight loss, malnutrition, frailty, sarcopenia and cognitive impairment are predictors of treatment complications (see these studies for examples) (Pujara et al., 2015; Chen et al., 2016).

It is important to identify patients who are frail; i.e. patients who are vulnerable to treatment complications, functional decline and poor survival (Rostoft, 2017). If the screening is positive, patients need a broader geriatric assessment which is more comprehensive and also includes emotional status, polypharmacy and social support. A discussion about goals of care is also necessary. Undergoing a geriatric assessment changes the treatment plan in 39% of older adults with cancer, in most cases to less aggressive treatment regimens (Hamaker

et al., 2014).

An additional consideration is that certain side-effects of cancer treatment, such as neuropathy from chemotherapy, can be debilitating and could push the patient from living in his/her own home to needing institutional care. A majority of older adults are not willing to trade living independently for life prolongation (Fried et al., 2002).

#### Essential requirements

- All older patients (70+) and patients who appear frail or have severe comorbidity must be screened with a quick, simple frailty screening tool, such as the adapted Geriatric-8 (G8) screening tool (Petit-Monéger et al., 2016) combined with measurement of 4 m gait speed (Clegg Rogers and Young, 2015).
- Frail patients must undergo a geriatric assessment (Wildiers et al., 2014). The assessment can be based on self-report combined with objective assessments that can be performed by a specialist nurse in collaboration with a physician (geriatrician/specialist in internal medicine).
- Cognitive impairment affects all aspects of treatment – ability to consent, compliance with treatment, and risk of delirium – and screening using tools such as Mini-Cog (Borson et al., 2003) is essential. A geriatrician or a geriatric psychiatrist or neurologist would preferably be involved, depending on local resources and traditions.
- In frail patients, the geriatrician must be present in the MDT meeting to discuss treatment options aligned with the patient's goals of care.

#### 3.5.3. Oncology pharmacy

Oncology pharmacy plays a critical role in the care of OG cancer, given the importance of systemic treatment and palliative care. Most patients will receive drug treatment, mostly chemotherapy, either in the perioperative setting (stages IB–III) as well as in the metastatic setting.

The role of the oncology pharmacist is to:

- Liaise with the medical oncologist to discuss pharmaceutical treatment regarding drug administration and patient-individualised changes in pharmacokinetics. In particular, drug administration into feeding tubes such as naso-gastric and PEG tubes is often used in patients with OG cancer
- Counsel patient about taking their drug treatment
- Supervise the preparation of oncology drugs.

#### Essential requirements

- Oncology pharmacists must be available to advise medical oncologists on complex pharmacological treatment of patients with OG cancer owing to common comorbidities and polypharmacy of patients and the higher risk of drug–drug interactions, changed kidney and liver function, and interaction with complementary medicines (e.g. herbal drugs).
- Oncology pharmacists must counsel patients on the correct way to take treatments such as oral oncology drugs.
- Oncology pharmacists must comply with the European QuapoS guidelines (European Society of Oncology Pharmacy, 2014). Oncology drugs must be prepared in the pharmacy and dispensing must take place under the supervision of the oncology pharmacist.

#### 3.5.4. Psycho-oncology

The prevalence and character of psychological distress in OG and gastrointestinal cancer patients have been reported in a few studies. For example, distress is common in patients with all stages of gastric cancer and is associated with worse outcomes (Kim et al., 2017). In gastrointestinal cancer patients, scores of 47.2% and 57% in anxiety and depression have been reported (Tavoli et al., 2007). Only minor

changes in anxiety and depression before and after surgery have been reported through the first year after surgery in this patient population, because of the persistence of symptom burden before diagnosis. Anxiety is more common in younger patients and depression in those who experience long-term hospitalisation.

The role of the psycho-oncologist is to:

- Ensure that psychosocial distress, psychological disorders and psychosocial needs are identified by screening and are considered by the MDT
- Promote effective communication between patients, family members and healthcare professionals especially before surgery and treatment relating to the consequences of lifestyle aspects (nutrition, smoking, exercise, uncertainty of prognosis)
- Support patients and family members in coping with multifaceted disease effects at all stages
- Evaluate psychosocial care programmes.

See also ‘Rehabilitation and survivorship’ and health-related quality of life issues.

### Essential requirements

- Screening for distress using a ‘distress thermometer’ must be carried out to identify patients with specific needs.
- Psychological interventions must be provided to all patients with OG cancer prior to surgery, during treatment and afterwards, especially to those who are identified as highly distressed.
- Interventions must include educative and cognitive-behavioural interventions to: reduce psychological distress and improve taking care of oneself; empower patients in lifestyle changes; deal with limitations caused by the disease and treatment; cope with survivorship issues such as return to work, and family and social involvement.

#### 3.5.5. Physiotherapy

Physiotherapists play a particularly important role in the management of patients with OG cancer. Many patients have significant respiratory comorbidity and reduced levels of physical fitness which can adversely affect their outcome particularly after major surgery. Physiotherapists are key to preoperative assessment but also in advising on preoperative exercise regimes. Their postoperative role in early mobilisation and respiratory intervention is part of the care pathway for all patients (Silva et al., 2013).

Essential requirements

- Qualified physiotherapists must be part of the initial clinical assessment of all patients planned for OG cancer surgery to identify a patient’s level of physical fitness and provide advice about physical activity including individual exercise programmes.
- There must be at least daily review of patients after surgery to assist with early mobilisation until the patient is independently mobile.
- All postoperative patients must be carefully evaluated to determine their needs for respiratory physiotherapy and appropriate intervention must be available at all times (24/7).

#### 3.5.6. Rehabilitation and survivorship

Survivorship, rehabilitation and supportive care are major issues for OG cancer patients and are increasing in importance not only as the number benefiting from curative treatment rises but also as the number of responders to advanced disease treatments increases. Some patients experience long-term problems related to their primary treatments such as difficulties with eating, nutritional deficiencies and disorders of digestion and bowel function.

A few studies have looked at health-related quality of life (HRQL) in OG patients (Conroy et al., 2006; Derogar and Lagergren, 2012; Schandl

et al., 2016). Trouble with eating, sleeping, talking and fatigue are common side-effects, especially in the initial period after surgery and treatment. Nutritional problems and weight loss can make family members distressed, as in most cultures eating is an essential sign of wellbeing and a unifying family ritual. Information about these issues must be communicated to patients and families to enable them to cope.

In general, late-effects from treatments and how patients’ lives are affected are not well understood. Cancer rehabilitation is crucial in helping people adapt to their condition and maximise function, independence and quality of life (Stubblefield et al., 2013; Ber et al., 2014; Scott et al., 2013).

### Essential requirements

- A multidisciplinary team involving clinicians, nurses, dietitians, psychologists and physiotherapists must discuss with patients and their carers the possible long-term effects of cancer treatment and the types of help available for them, i.e. nutritional support including management of disorders of digestion and physical activity.
- Rehabilitation and survivorship must be integrated into care pathways to ensure the best possible care continues beyond treatment.
- Professionals must use a person-centred, goal-setting approach, empowering the patient and their carers to take control of their rehabilitation.
- Rehabilitation and survivorship must be integrated into national cancer plans and must include policies concerning welfare, employment and financial services.

## 4. Other essential requirements

### 4.1. Patient involvement, access to information and transparency

Patients must be involved in every step of the decision-making process. Their satisfaction with their care must be assessed throughout patient care pathways. It is also essential that patient support organisations are involved whenever relevant. Patients must be offered information to help them understand the treatment process from the point of diagnosis. They must be supported and encouraged to engage with their health team to ask questions and obtain feedback on their treatment wherever possible.

Currently there are few dedicated patient groups for OG cancers in Europe, but many groups that cover all cancers. Among the dedicated groups in Europe:

- In 2015, the pan-European group EuropaColon (europacol.com) extended its remit to all digestive cancers and will be expanding support services for OG patients
- The UK has the Oesophageal Patients Association (opa.org.uk), which was established in 1985, and has an example care pathway on its site; and also the Barrett’s Oesophagus Campaign (sites.google.com/site/barrettsoesophaguscampaign), which supports the UK National Barrett’s Registry (UKBOR). Macmillan has active online groups for most cancers (<https://community.macmillan.org.uk/groups>)
- An Italian stomach cancer group is Vivere Senza Stomaco (viveresenzastomaco.org)
- A group in Germany is Ratgeber Magenkrebs Speiseröhrenkrebs (<https://ratgeber-magenkrebs-speiserohrenkrebs.de>).

The European Society for Medical Oncology (ESMO) has patient guides on oesophageal and stomach cancers available in a number of languages (<http://www.esmo.org/Patients/Patient-Guides>) and also a patient guide on survivorship (<http://www.esmo.org/Patients/Patient-Guides/Patient-Guide-on-Survivorship>) produced with the European Cancer Patient Coalition (ECPC, <http://www.ecpc.org>).

Conclusions on each MDT case discussion must be made available to

patients and their primary care physician. Advice on seeking second opinions must be supported.

Cancer healthcare providers must publish on a website, or make available to patients on request (such as by providing official audit reports), data on centre/unit performance, including:

- Information services they offer
- Waiting times to first appointment
- Pathways of cancer care
- Numbers of patients and treatments at the centre
- Clinical outcomes
- Patient experience measurements (PREMs)
- Incidents/adverse events
- Clinical trials.

#### 4.2. Performance and quality

The ERQCC expert group recommends that OG cancer centres develop:

- Performance measurement metrics/quality indicators based on the essential requirements in this paper
- Operational policies to ensure the full benefits of a coordinated clinical pathway based on published guidelines
- Accountability within the governance processes in individual institutions
- Systems to ensure safe and high-quality patient care and experience throughout the clinical pathway
- Effective data management and reporting systems
- Engagement with patients, their carers and support groups to ensure reporting of patient outcomes and experience.

To fully assess the quality of OG cancer care, three categories of outcomes must be measured and collected in databases at the OG centre, regionally and/or nationally:

- Clinical outcomes
- Process outcomes
- Patient-reported outcomes (PROs) – in accordance with developing standards.

This includes national audits where available and national cancer registration/certification.

These approaches can be developed in the context of quality management systems (QMS) depending on the health economy of an individual country. The benefits of such a system include:

- Improving processes to enhance patient safety
- Setting standards within a clinical pathway
- Ensuring appropriate resource management including workforce and financial resources
- Facilitating training opportunities
- Determining optimal outcomes with appropriate audit
- Establishing quality of life of patients following treatment.

##### 4.2.1. Audit of outcomes

Data measured and collected varies among countries but it is recommended that these outcome metrics are systematically measured and collected for audit:

- % of preoperative patients discussed in the MDT
- % of postoperative patients discussed in the MDT
- Proportion of patients according to clinical stage at time of diagnosis
- Proportion of patients receiving treatment with curative and palliative intent
- Number of curative procedures

- Complications
- In-hospital mortality
- 1 and 5 year overall survival rate
- Adherence to MDT recommendations.

##### 4.2.2. Multidisciplinary team performance

- All MDT decisions must be documented in an understandable and timely manner, and must become part of patient records. Decisions taken during MDT meetings must be monitored, and deviations reported back to the MDT. It is essential that all relevant patient data, such as pathology reports, meet quality standards and are available at the time of the MDT meeting.
- The core and extended MDTs must meet at least twice a year to review the activity of the previous period based on the audited metrics, discuss changes in protocols and procedures, and improve the performance of the unit/centre. MDT performance must be quality assured both internally and by external review with demonstration of cost-effectiveness of quality improvements, and MDT guidance must be promoted nationally and written into national cancer plans.
- The ERQCC expert group strongly recommends that further attention must be given to measures of PROs, not only to agree which tools should be used, but also to use PROs more systematically as part of discussions and evaluation within the MDT.

##### 4.2.3. Accreditation

The ERQCC expert group strongly recommends participation in national or international accreditation programmes, e.g. Organisation of European Cancer Institutes (OECI) accreditation (<http://oei.selfassessment.nu/cms>) (Wind et al., 2016) and European Cancer Centres (<https://www.krebsgesellschaft.de/gcs/european-cancer-centres.html>).

The ESMO Designated Centres of Integrated Oncology and Palliative Care accreditation programme started in 2003, under which cancer centres can receive special recognition for achieving a high standard of integration of medical oncology and palliative care. This initiative is particularly relevant to the high rate of incurable cases of OG cancer (<http://www.esmo.org/Patients/Designated-Centres-of-Integrated-Oncology-and-Palliative-Care>).

##### 4.2.4. National examples

Listed below are several national quality and audit resources.

- The National Oesophago-Gastric Cancer Audit for the NHS in the UK, which began in 2006, covers the quality of care given to patients with OG cancer and oesophageal high-grade dysplasia. It is based on nationally developed clinical guidelines (Allum et al., 2011). The report on the year 2016 flags up two concerns: a significant proportion of patients with high-grade dysplasia is managed by surveillance alone instead of endoscopic or surgical treatments as recommended; and there is variation in care in terms of routes to diagnosis, the reported use of staging investigations, and proportion of patients managed with curative intent (NHS, 2016).
- A report on the reorganisation of OG cancer networks in England and Wales under the national cancer plan reform found that centralisation of surgery had improved, as had specialist nutritional support, but the involvement of palliative care in MDTs was lacking in 20% of hospitals. A paper on the survey provides detailed information on MDT working and questions asked about access to procedures and expertise (Groene et al., 2014).
- Germany has a voluntary certification system that covers the majority of cancers, set up by the German Cancer Society (<http://www.ecc-cert.org>). The system has been adopted by the German National Cancer Plan. Certified cancer centres include those that qualify as a multidisciplinary gastric cancer centre. The certification of gastric

cancer centres started in 2014: there are currently 28 certified centres in Germany and 1 in Switzerland. Certification is based on the current S3 guideline for gastric cancer (Moehler et al., 2011) and there is a catalogue of structural and quality criteria that must be fulfilled by a site to obtain and maintain the certificate – e.g. centres have to treat at least 30 new surgical cases per year. Treatment decisions must be taken by a MDT, and there are quality indicators. The centres are audited annually by independent experts and the results published in a benchmark report. Certification of oesophageal cancer centres is planned, based on the S3 guideline.

- The Dutch Upper Gastrointestinal Audit (DUCA) started in 2011 and provides surgical teams with benchmarked information on process and outcome measures. A paper reporting early outcomes from the project shows a significant increase in the percentage of oesophageal cancer patients starting treatment within 5 weeks of diagnosis, and an increase in the percentage of patients with at least 15 examined lymph nodes in both oesophageal and gastric cancers (Busweiler et al., 2016). However, a recent paper found that a ‘textbook outcome’ for patients included in the audit was achieved in only about 30% of patients with oesophageal cancer and 32% of those with gastric cancer. The outcome parameter, ‘at least 15 lymph nodes examined’, had the greatest negative impact (Busweiler et al., 2017).
- Belgium’s Healthcare Knowledge Centre (KCE) has published quality indicators for managing OG cancers to support clinical guidelines and recommendations for centralising care (services have been widely dispersed in Belgium) (Vlayen et al., 2013). Following assessment, a final list of 15 quality indicators for oesophageal cancer and 14 quality indicators for gastric cancer was drawn up. KCE notes that according to Avedis Donabedian’s classification, quality indicators are categorised by process (what is actually done in giving and receiving care), outcome (states of health or events that follow care, and that may be affected by healthcare) and structure (characteristics of providers and the healthcare system that affect the system’s ability to meet the healthcare needs of individual patients or a community) (Vlayen et al., 2006). The indicators selected for Belgium are process and outcome indicators – no structure indicator was selected. These quality dimensions are covered: effectiveness, appropriateness, continuity, safety, timeliness and patient-centredness. No indicator addressed efficiency or equity.

#### 4.2.5. The EURECCA project

- At European level, a consortium of cancer societies, including ECCO, have started a quality improvement programme, European Registration of Cancer Care (EURECCA), which initially focused on colorectal cancer. It aims to be a ‘trademark’ for quality assurance in cancer management in Europe. It has extended its work to other cancers, including OG (termed upper GI in this project), and has a number of projects in this category including European comparison of treatment and outcome of older patients with resectable cancers, D2 gastrectomy compliance, and international comparison of treatment.
- The EURECCA upper GI project published a paper in 2016 that charted variation among 5 countries on curative treatment of OG cancers based on a common dataset, and was a ‘proof of concept’ that variations and commonalities can be reported in a collaborative way (Messenger et al., 2016b).
- Since then more data has been collected on organisational – not just surgical – practice in 10 countries, showing for example variations in the technologies used to stage OG cancers, and that 8 countries report that all patients are discussed by an MDT but 2 countries – Italy and Poland – report only 50% and 25% respectively (Messenger et al., 2016a). Treatment is carried out within 1–3 weeks of the MDT meeting, and mostly in specialist centres, but there are shortcomings in pre-assessment (for example all countries report carrying out

pulmonary tests but only half do a smoking and alcohol review and only 4 provide psychological help at this point).

- Only half of the 10 countries have implemented enhanced recovery after surgery (ERAS) programmes, which are seen as a ‘paradigm shift’ in perioperative care, ‘resulting in substantial improvements in clinical outcomes and cost savings’ (Ljungqvist et al., 2017), and are especially applicable to complex care required for OG cancer treatment. The ERAS Society has guidelines for aspects of upper GI surgery (<http://erassociety.org>).
- Among other variations, specialist nurses are available in only half of the countries.

## 5. Cancer education and training

It is essential that each OG cancer centre provides professional clinical and scientific education on the disease and that at least one person is responsible for this programme. Healthcare professionals working in OG cancer must also receive training in psychosocial oncology, palliative care, rehabilitation and communication skills. Such training must also be incorporated into postgraduate and undergraduate curricula for physicians, nurses and other professionals. Collaborative opportunities should be available for trainees from all professional backgrounds to gain experience by exchange between countries.

## 6. Clinical research

- Institutions active in research can achieve better outcomes for the entire patient group rather than just the research participants (for example in colorectal cancer) (Downing et al., 2017). Centres treating OG cancers must have clinical research programmes (either their own research or as a participant in programmes led by other centres). The MDT must assess all new patients for eligibility to take part in academic and industry sponsored clinical trials at the centre or in research networks. Collaboration with European academic networks is strongly recommended – see the European Organisation for Research and Treatment of Cancer (EORTC – <http://www.eortc.org>) and the European Clinical Research Infrastructure Network (ECRIN – <http://www.ecrin.org>).
- EURECCA’s upper GI project asked about surgical academic work in its 10-country survey, finding wide variation in patients screened for clinical trial participation and those included, with Denmark having the highest percentage of both patients screened and included in studies.
- Clinical trial enrolment for OG cancers can be difficult owing to moderate to low incidence. Collaboration between high volume centres and community hospitals is needed to identify patients for clinical trials. Innovative study designs can be explored to develop more efficient and targeted clinical trials that will detect large differences (Lin and He, 2015).
- Correlative biomarker research is a crucial part of all phases of clinical studies, and requires close cooperation among clinicians, especially surgical and pathology teams, and with biologists and biobanks within research networks such as EORTC’s SPECTA programme (<http://www.eortc.org/other-research-initiatives/specta>).
- Patient-reported outcomes, especially concerning quality of life, must be included as endpoints in clinical trials. This is of particular importance for OG cancers, as they have a high incidence of disease-related symptoms but also a high incidence of treatment-associated morbidity.
- For OG cancers, centres should have at least 5% of all patients included in clinical research. Members of the research teams (clinicians, scientists or nurses) from other centres should be considered as part of the extended MDT for at least a bi-annual discussion of clinical trial participation. Older adults, in particular frail older adults, are currently underrepresented in cancer clinical trials

despite having a disproportionate burden of disease (Kaźmierska, 2013). Strategies to increase the participation of older adults in clinical trials must be implemented and trials designed to take into account their needs (Wildiers et al., 2013).

- FREGAT (French EsoGastric Tumours – <https://www.fregat-database.org>) is a good example of a national clinic-biological prospective database that is collecting data and samples from patients with OG cancers in France. It will include data on access to care and quality of life.

## 7. Conclusion

Taken together, the information presented in this paper provides a comprehensive description of the essential requirements for establishing a high-quality OG cancer service. The ERQCC expert group is aware that it is not possible to propose a ‘one size fits all’ system for all countries, but urges that access to multidisciplinary units or centres must be guaranteed for all those with OG cancers.

## Conflict of interest

The authors declare no conflicts of interest.

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