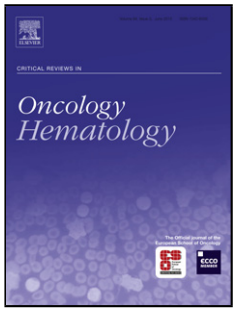

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Authors: Ian Banks, David Weller, Mehmet Ungan, Peter Selby, Matti Aapro, Marc Beishon, Marije Bolt, Fiona Bonanno, Claire Champeix, Csaba Dégi, Lisa Jelf Eneqvist, Joanna Kazmierska, Agnieszka Kolacinska, Simon Malas, Sébastien Moine, Danica Rotar Pavlic, Richard Price, Fiona Walter, Lynda Wyld

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ECCO Essential Requirements for Quality Cancer Care: Primary care

Ian Banks[1], David Weller[2], Mehmet Ungan[3], Peter Selby[4], Matti Aapro[5], Marc Beishon[6], Marije Bolt[7], Fiona Bonanno[8], Claire Champeix[9], Csaba Dégi[10], Lisa Jelf Eneqvist[11], Joanna Kazmierska[12], Agnieszka Kolacinska[13], Simon Malas[14], Sébastien Moine[15], Danica Rotar Pavlic[16], Richard Price[17], Fiona Walter[18], Lynda Wyld[19]

[1]European Cancer Organisation Patient Advisory Committee (ECCO PAC); European Men's Health Forum

[2]World Organization of Family Doctors (WONCA Europe); Centre for Population Health Sciences, University of Edinburgh, Edinburgh, United Kingdom

[3]World Organization of Family Doctors (WONCA Europe); Department of Family Medicine, Ankara University School of Medicine, Ankara, Turkey

[4]European Cancer Concord (ECC); Leeds Institute of Cancer and Pathology, Leeds, United Kingdom

[5]European Cancer Organisation (ECCO); Genolier Cancer Centre, Clinique de Genolier, Genolier, Switzerland

[6]Cancer World, European School of Oncology (ESO), Milan, Italy

[7]Council of Occupational Therapists for European Countries (COTEC)

[8]European Society of Oncology Pharmacy (ESOP); Sir Anthony Mamo Oncology Centre, Malta

[9]Eurocarers

[10]International Psycho-Oncology Society (IPOS); Faculty of Sociology and Social Work, Babes-Bolyai University, Cluj-Napoca, Romania

[11]European Oncology Nursing Society (EONS); Regional Cancercenter Stockholm-Gotland, Sweden

[12]European Society of Radiotherapy and Oncology (ESTRO); Radiotherapy Department II, Greater Poland Cancer Center, Poznan, Poland

[13]European Society of Surgical Oncology (ESSO); Department of Head and Neck Cancer Surgery and Surgical Oncology, Medical University of Lodz, Lodz, Poland

[14]Association of European Cancer Leagues (ECL); Oncology Clinic, Limassol General Hospital, Limassol, Cyprus

[15]European Association of Palliative Care (EAPC); Education and Health Practices Laboratory, University of Paris, France

[16]European Forum for Primary Care (EFPC)

[17]European Cancer Organisation (ECCO)

[18]Primary Care Unit, Department of Public Health and Primary Care, University of Cambridge, United Kingdom

[19]European Society of Breast Cancer Specialists (EUSOMA); Department of Oncology and Metabolism, University of Sheffield, Sheffield, United Kingdom

Highlights

- Primary care plays a major role in the diagnosis of cancer and care of patients
- Primary and community care are often not well integrated into cancer care
- There are many opportunities for extending care at the primary level
- Healthcare systems must consider new roles for primary and community professionals

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 cancer patients. They are written by European experts representing all disciplines involved in cancer care. This paper concerns the integration of primary care into care for all cancers in Europe.

Primary care integration

- Primary care professionals play major roles in the diagnosis of cancer and care of cancer patients.
- There are many opportunities for extending care at the primary level to cope with the increasing cancer burden and its nature as a chronic disease, but there are also significant barriers to progress towards high-quality patient-centred care.
- To meet European aspirations for comprehensive cancer control, healthcare organisations must consider the requirements in this paper to include primary and community care in patient-centred pathways from diagnosis to treatment and survivorship.

1 Introduction: the need for quality frameworks

There has been a growing emphasis on driving up quality in cancer organisations given variations in outcomes in Europe. The European Cancer Concord (ECC), a partnership of patients, advocates and cancer professionals, has recognised major disparities in the quality of cancer management and in the degree of funding in Europe in its 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.[1]

This followed an assessment of the quality of cancer care in Europe as part of the first EU Joint Action on Cancer, the European Partnership for Action Against Cancer (EPAAC, http://www.epaac.eu), which reported 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 having 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.*[2] This recognised that community level integrated cancer care, and survivorship and rehabilitation, are two of four key areas to address, alongside cancer screening and comprehensive cancer care networks, which focus mainly on diagnosis and treatment.

1.1 The ERQCC approach and primary care

Other papers in the ECCO Essential Requirements for Quality Cancer Care (ERQCC) series have addressed the need to establish multidisciplinary centres to treat and care for patients with certain tumour types. But a consistent theme is the many challenges in extending care before and after diagnosis and treatment at the community and primary care level to cover the entire patient journey – to provide the best prevention, the most-timely diagnosis, and to support patients and families in the course of their treatment and as survivors, and, for many, in end of life care.

This theme is increasing in importance as cancer care moves towards chronic disease management and as an international evidence base builds for the effectiveness of primary care, with the role of the primary care physician changing to a care commissioner and coordinator rather than a lone practitioner. Notably, the expanding role of primary care in cancer control was analysed in a Lancet Commission of 2015, which said that, 'The strengths of primary care – its continuous, coordinated, and comprehensive care for individuals and families – are particularly evident in prevention and diagnosis, in shared follow-up and survivorship care, and in end-of-life care.'[3] But the readiness of, and resources available to, primary care practices to manage the often specialist requirements of cancer patients and survivors are in early stages in most countries, even though health systems are placing increasing emphasis on minimising care in acute settings, not least because of cost.

This ERQCC paper address primary care requirements with respect to these questions:

- What type of primary care action/intervention should be available/delivered to cancer patients?
- Which primary care professionals should be involved (roles and responsibilities of professional groups, such as GPs, pharmacists, community nurses and allied health professionals)?
- When and at what stage of the cancer care continuum should primary care actions/interventions should be available (including during treatment)?
- How should an intervention be delivered/made available?
- What is needed from an organisational point of view to deliver these interventions?

The key essential requirement put forward in this paper is that, given that primary care is central to effective health reform, a multiprofessional team of general practitioners, nurses, community pharmacists, carers and other primary or community professionals must be considered as part of the extended multidisciplinary team (MDT) in cancer care pathway planning in all countries.

2 Models of integrated care – a cancer perspective

The integration of primary care with cancer treatment services can be seen in two key areas: referral for diagnosis and treatment, and care during and after treatment.

2.1 Diagnosis

While some cancers have effective screening programmes that may detect a significant number of cancers, primary care still plays the major role in the diagnostic process. Pathways for making timely referrals to specialist cancer services are vital for improving outcomes, but are complex to implement given that many cancer symptoms are vague, and that cancer types vary significantly in the need for urgency.

Guidelines and decision support tools are vital if referral pathways are to be optimised and the burden on specialist services minimised. For example, the UK's National

Institute of Health and Care Excellence (NICE) produces cancer referral guidelines for suspected cancer; in its 2015 updated guideline for suspected cancer, there are lowered symptom-based risk thresholds for cancer referral (and even lower for children and young adults).4 Further, signs and symptoms of cancer are organised more effectively, according to how patients typically present, and GPs are given more flexibility to refer patients directly for 'open access' investigations such as colonoscopy and CT scans. There is early evidence for one expected benefit – a reduction of cancers diagnosed in emergency departments, which can be high for cancers such as lung5 and colorectal cancer.

Over the past decade or so, more cancer decision support tools have become available for GPs, although their implementation and uptake is variable.6 These have the potential to support decisions over whether to refer for suspected cancer, by providing risk estimates based on symptoms and other patient factors, and can help address the challenges of overdiagnosis and overtreatment.7

2.2 Integrated care during and after treatment

Care for patients undergoing treatment or as a cancer survivor are major issues given the volume of patients, especially older people with a number of co-morbidities, and the increasing range of treatments. The extent of support and follow-up needed for patients varies greatly in both physical and psychosocial factors.

Integrated care models are seen as solutions to the challenges. The World Health Organization (WHO) Europe has noted that integrated care can improve patient experience and health outcomes of multimorbid and long-term care patients. But there is a multiplicity of definitions and conceptual frameworks – one literature review uncovered some 175 overlapping definitions and concepts of integrated care, indicating the absence of consensus for its definition.8 The WHO notes both process and user-led definitions, with a good example of the latter employed in England:9

"My care is planned with people who work together to understand me and my carer(s), put me in control, coordinate and deliver services to achieve my best outcomes."

The WHO document describes various models, including individual care plans, patient-centred medical home care (which in the US has shown a 20% reduction in hospital admissions and 12% reduction in readmission rates); group-based models, such as the chronic care model and care models for older and frail people; and disease-based models.

In European countries, there is a lack of harmonisation between primary and secondary care; for example, patients are often discharged without adequate planning, with emergency readmissions and compromised patient outcomes as a result.10 In the UK, integrated care pathways have been proposed as a way to improve support for these patients, especially for older patients whose needs are more complex, and are recommended in 'Achieving world-class cancer outcomes: a strategy for England 2015-2020.[13] The strategy also puts forward the idea of a 'recovery package' for people living with cancer and/or consequences of treatment, and also 'stratified' follow-up pathways that can help to tailor care to patients' needs and reduce costs by, for example, reducing many outpatient appointments, and identifying opportunities for community based care.11

Another term often used in this context is 'shared care', meaning primary care professionals working with the acute sector to share information and care for a patient's cancer, which is increasingly recognised as a chronic condition.12 In these models each patient should have a care plan that covers their cancer journey, which in future is likely to be managed by a primary care and social welfare team, in collaboration with cancer centres.

There is a rapidly expanding literature base on topics such as primary care-led models of follow-up and survivorship care, although much currently emanates from North America.13 There is little international consensus on ideal models of post-treatment cancer care, and it is not the purpose of this paper to explore these models – they are often specific to health and social care systems in individual countries. Nevertheless, such models provide a rich evidence base, and underpin the components of and opportunities for primary care we set out. The appendix lists examples of national projects that are instructive for cancer and primary care.

3 Cancer in Europe: key facts

3.1 Epidemiology – the scale of European cancer burden

- In 2018, 3.9 million new cases of cancer (all types, excluding non-melanoma skin cancer) and over 1.9 million cancer deaths were estimated in the European region.14 In the European Union (EU), cancer is the second leading cause of mortality after cardiovascular diseases. Lung, colorectal, female breast, pancreas and prostate cancers account for nearly half (49%) of all deaths due to cancer.15
- About 1.3 million people died from cancer in the EU in 2014, which equated to more than one quarter (26.4%) of the total number of deaths. Cancer accounted for a higher share (29.7%) of deaths among men than among women (23.2%). Mortality rates differ widely among countries – the highest standardised death rates for cancer were recorded in Hungary, Croatia and Slovakia, each with rates over 320 per 100,000 inhabitants in 2014; the lowest rate was in Cyprus, at 207 per 100,000.16
- The EUROCARE-5 study reports that the number of adults surviving for at least 5 years after diagnosis had risen steadily over time in all European regions from 1999 to 2007. But survival still varies widely between European countries. Eastern Europe has the lowest survival for most cancers, and particularly for colorectal cancer, lymphomas and skin melanoma. Nordic countries (with the exception of Denmark), central European countries such as Austria, Belgium, France, Germany, Switzerland, and Netherlands, and some countries in southern Europe (Italy, Portugal, and Spain), have the best survival for most cancers.17
- Childhood cancer remains a significant public health issue, notes EUROCARE. Survival at 5 years from diagnosis for children (0-14 years) for all cancers is 79% now surviving (2005–2007), up from 76% in 1999–2001. However, no progress has been achieved for those paediatric malignancies with the poorest prognosis and there are unacceptable disparities in the survival of children and adolescents with cancer across the continent: survival in Eastern Europe is generally 10% to 20% lower than in Western Europe.18

3.2 Costs of cancer

Health expenditure on cancer increased continuously from €35.7 billion in 1995 to €83.2 billion in 2014 in the EU and spending on cancer drugs from €7.6 billion in 2005 to €19.1 billion in 2014 (based on prices in 2016).19 While expenditures on cancer drugs increased in both absolute and relative terms, other expenditures were stable or decreased, despite increases in cancer incidence driven by a growing and ageing population. An earlier study also estimated the costs of primary care for cancer, finding that primary, outpatient and emergency care together accounted for less than 20% of cancer-related healthcare costs, and also that unpaid, informal care in cancer was substantial, at €23 billion.20 A comparison of the value of cancer care has found that care in the United States may provide less value than corresponding cancer care in Western Europe for many leading cancers, with implications for focusing on high-value care in prevention, screening and palliative care, where primary care has major roles.21

3.3 Changing nature of cancer treatment and extent of survivorship

In many respects, treatments for cancer have been a major success as the survival for many cancer types has increased greatly according to new approaches applied by

MDTs in cancer centres, including new surgical, radiotherapy and drug treatments. While new treatments aim to minimise side-effects and long-term morbidity, there are increasing numbers of patients living with conditions arising from their treatment, new types of adverse events, and a rise in oral drugs taken at home.

For example, in breast cancer 5 year survival rates have increased from 50% 40 years ago, to over 80%. As a result there is a large number of breast cancer survivors in Europe. In the UK alone, there were estimated to be 570,000 breast cancer survivors in 2010, predicted to rise to 840,000 by 2020 and to more than 1.6 million by 2040.22 However, surviving breast cancer comes at a cost. Many of the treatments have long-term side effects which may have a significant negative impact on quality of life (QoL). Some of the major adverse events impairing QoL are the early induction or worsening of menopause, osteoporosis, genitourinary syndrome of the menopause, long-term depression and anxiety, and body image issues due to loss of the breast or scarring. Many of these impacts will need to be managed in primary care or with shared care arrangements with secondary care.

Similar long term survivorship issues could be cited for all other cancer types.

4 Opportunities and challenges for cancer in primary care

4.1 Detection and prevention

- Primary care professionals have a key role in encouraging people to seek early help for symptoms, countering fears and worries about wasting a doctor's time.23
- Most primary care physicians see about the same number of cancer cases a year as new cases of diabetes, but most cancer cases are common types such as breast and lung – they may not see a rare cancer (such as sarcoma or brain tumour) at any point of their career. This has implications for early referral and diagnosis, and also for follow-up and community care. In England, 21% of cancers are diagnosed as an emergency, which is associated with advanced tumour stage and increased mortality in the first year after diagnosis.24 However, the number of cancer cases will increase – projections in the UK, for example, have shown that a primary care physician will see twice as many cancer patients by 2040.[23]
- The workload on primary care physicians varies and can greatly exceed what is considered to be a manageable and safe level of daily patient contacts.25
- There should be access to and sustainability of prevention programmes such as stop smoking services, sun awareness, healthy eating and weight management, reducing alcohol intake and promoting exercise, given that about 40% of cancers are caused by lifestyle factors.
- Screening programmes for three cancers – breast, cervical and colorectal – are currently implemented at population level in a majority of European countries. These programmes typically function independently of primary care, ignoring opportunities for primary care to enhance screening – in promoting uptake, information provision and informed choice.26 It could also be of value to reduce screening activity in the frail or unfit where overdiagnosis may be an issue (breast cancer for example). Primary and community care are though increasingly involved in some screening and prevention measures, such as administering the HPV vaccine against cervical cancer, and in cervical screening.
- Certain cancer specific knowledge can be lacking in primary care, for example on tamoxifen chemoprevention in breast cancer.27,28
- Knowledge about genetic risk factors will become increasingly important for primary care.

4.2 Healthcare structure barriers

- There is often a lack of integration between primary and secondary/acute care and also among the primary care sector such as between GPs and community pharmacy, with implications for IT systems, care pathways, lack of resources at hospital level for follow-up, and after discharge in the community.29,30

- A major issue in many countries is lack of integration between the health and social care sectors.
- Services can be hard for patients and carers to navigate, especially for those with poor health literacy or cognitive impairment.
- Many patients in Europe face poor geographical access to care, especially in more sparsely populated areas, where local primary care provision may assume greater importance.
- Communication between doctors and patients can be poor at all tiers of healthcare.
- Cancer patients often express frustration with the fragmentation of their care.
- Differences in status between specialist cancer physicians and primary care professionals can be a barrier.
- In Central and Eastern Europe there is often overprovision of costly in-patient care in hospitals at the expense of outpatient and community care that is more suited to cancer treatment and patient preferences.[31,32]

4.3 Treatment and side-effects

- GPs can be advocates in treatment decisions taken by MDTs at cancer centres as they often know the patients and their wishes best. This is especially important in the management of patients with cognitive or mental health impairment where their input may be valuable in decision making and liaison. There are, however, often financial and organisational barriers to GP participation in MDT meetings.
- Surgical, drug and radiation-induced side-effects are common in cancer and patients are likely to make more demands on their primary care team during and after treatment. Co-morbidities are common – the majority of over-65s have 2 or more conditions, and the majority of over-75s have 3 or more conditions. Optimisation of these chronic co-morbidities before cancer treatment may enable improved outcomes, for example diabetes or hypertensive control optimisation before and after surgery. The management of shared cancer care between primary and secondary levels during treatment and after hospital discharge undoubtedly puts pressure on lines of accountability and patients may fall between gaps.
- The number of oral anticancer agents has been growing rapidly and while patients appreciate the convenience and independence from medical facilities and being reminded less of their disease, adherence to the drug regimen can be challenging for some. This is also a challenge for integration among medical oncologists, hospital-based oncology pharmacists, and primary care professionals including GPs, community pharmacists and community nurses.
- Pain management and palliative care must be provided for those with advanced cancer.33 Currently, only a minority of European patients have access to a specialist pain clinic34 and access to opioids has been found to vary greatly in Europe.35

4.4 Follow-up, survivorship and rehabilitation

- Follow-up of cancer survivors is essential to detect recurrences and to manage longer term side-effects and quality of life.36 This can be challenging for primary care teams with limited oncology training, although trials in colon and breast cancer have shown equivalent outcomes with hospital-based care.37 While guidance and information on optimal patient pathways is increasing, more information for primary care physicians is needed on the best way to provide aftercare for cancer survivors in most countries.[3]
- Long-term chronic illness and conditions that result from treatment are likely to put pressure on primary care and community resources, but rehabilitation and support services provided by community nurses and social workers can help to fill gaps in managing conditions. Older and frail people are at particular risk as treatment may increase their level of dependency on social care support, which may need to be coordinated by both primary and secondary care. But social care is often inadequately funded.

- Strategies that help to empower patients to take an active self-management role in their care (should they wish to) have been shown to be advantageous, as with other chronic illnesses.38

4.5 Psychosocial support

- Many cancer patients suffer psychological distress after diagnosis and in survivorship. Psychological interventions and psychosocial support must be offered to patients, and their families and carers, throughout their cancer journey.

4.6 Return to work and financial burdens

- Given the rising number of cancer survivors and patients of working age, there is a role for community-based professionals to assist in enabling return to employment, either full time or part time, and in reassigned duties, where appropriate. Occupational health professionals, for example, are important to return to work strategies for cancer patients, but provision is patchy and there may not be cancer-specific support apart from other chronic conditions.
- There are few studies that have looked at the role of GPs – one systematic review found that lack of communication between healthcare professionals, lack of knowledge about work-related concerns and limited resources were recurring themes in those studies that were identified, and there is a call more research.39
- Insurance and welfare systems are crucial for supporting cancer patients.

4.7 Carers

- Much of the burden of community and home care for cancer patients rests on informal or family carers, many of whom may be frail or older themselves. They often transport the patient to and from hospital appointments, sit in on consultations and assist in decision making (especially if the patient has cognitive impairment) and may help in administering care (for example special diets, administering or fetching medications and dressings), and in financial support. Many carers have to take time off work to support relatives and receive no financial compensation.
- Enhanced recognition of the role of carers, better support and respite provision and recognition in an integrated care pathway would help to address the needs of carers, but currently they are a major and often poorly supported group and must be included in medical, psychological and welfare support strategies.

4.8 Palliative and end of life

- The early integration of palliative care has been shown to improve quality and length of life for those with terminal cancer and primary care is well placed to ensure it does start at an appropriate time. Primary palliative care teams can help meet physical, social, psychological and spiritual needs of patients and carers and can reduce hospital admissions and increase the chances of dying at home.
- There is a growing amount of information and guidance for community based models of palliative care.40,41

4.9 Inequalities

- There are widespread inequalities in access to primary care teams and secondary/tertiary care in Europe.
- People from disadvantaged backgrounds tend to fare worse in referrals and access to care.
- Older people often do not receive the standard of care owing to a lack of geriatric assessment.
- Younger people and children have special needs that can be overlooked.

4.10 Education and training

While cancer care has become highly specialised and increasingly personalised, the primary care workforce needs education and training in all treatment related issues,

and risk factors, screening, genetic testing, and in specific shared care work undertaken in primary care in supportive and palliative care, and rehabilitation.

4.11 Research

There is a lack of survivorship research and patient reported outcomes that could help integrate primary care; it is recognised that long-term cancer survivorship care is a relatively new but rapidly advancing field of research.42

4.12 Cancer registration and data availability

Cancer registration practice, coverage and quality are highly unequal across Europe.43 Consequently, basic epidemiological data on incidence, mortality and survival are not uniformly available for all countries. Also, only a minority of cancer registries can provide sufficient data for the calculation of parameters necessary for the assessment of outcomes and quality of care.44 An inability to register cancer recurrences, for example, means that health and social systems do not have numbers needed to plan certain support services, including primary care.

Case study – early and metastatic breast cancer
Treatment of breast cancer is increasingly complex, with multidisciplinary care stratified according to algorithms that take account of tumour biology, tumour stage and patient preferences. About 30% of patients are over the age of 70, which adds another layer of complexity as clinicians attempt to optimise care for fitness and frailty.45 Women with metastatic breast cancer often have significant health and social support needs as their health declines to the point of requiring end of life care. Breast cancer care must therefore span health domains, with sophisticated provision across primary, secondary and social care. Care can be expensive and poorly planned care may lead to unplanned admissions, delayed discharge or adverse events. Investment in treatment planning with integrated care pathways, management algorithms and key workers to plan care may improve outcomes, quality of life, survival, and reduce costs.
Early breast cancer
Primary care is integral to the care pathway in facilitating early diagnosis by prompt referral and by coordination of screening programmes; optimisation of fitness prior to surgery (diabetes and hypertension control optimisation); psychological support; shared care regimes for post-surgical discharge, follow-up and chemotherapy care; prescribing and monitoring longer term medication; and diagnosing and referring recurrence. Many women also require social support during their cancer journey; many are of working age or have dependants or children and may suffer financial loss as a result of treatment-related incapacity. Social support to aid in financial and other difficulties may be required. Extended members of the care team may also be required such as physiotherapy for women who have undergone complex reconstructive surgery or axillary clearance. For the one third of all cancers that occur in women over age 70 there may be pre-existing frailty and multimorbidity or dementia to manage which may require input from social care providers, geriatricians, primary care doctors and nurses and, critically, the patient's carers (informal family and friends and formal carers).
Metastatic breast cancer (MBC)
Treatment is complex and often involves multiple lines of therapy following a big expansion in anti-cancer agents, with periods of good quality of life between treatment spells. MBC survival has been increasing in most age groups with the exception of women over 70. The illness trajectory of MBC is complex, moving from presymptomatic to symptomatic (stable, unstable, acute or crisis), treatment induced recovery, further symptoms and finally decline and death.46 Treatments are sequential and complex to administer and support, and care is costly. Acute crises include spinal cord compression, hypercalcaemia, pathological fracture, confusion and neutropenic sepsis. These events are likely to require urgent admission and prolonged in-patient care and high support needs to facilitate discharge,

with extensive involvement of primary and community care teams (GPs, physiotherapists, community nurses, palliative care teams, community pharmacy, social care and carers).

5 Primary and community care requirements

5.1 Primary care physicians/GPs

Primary care physicians, or general practitioners (GPs) are the gatekeepers to the health system in many countries. Primary care is undergoing important transitions in many European countries – it needs to cope with ageing populations and, typically, patients with multimorbidity. GPs are increasingly recognised as expert generalists, with key roles in coordinating care with the patient as the focus. Primary care clinics have changed over recent decades (solo practice is now relatively uncommon); they typically comprise teams of healthcare providers supported by electronic medical records and multidisciplinary care opportunities.47

With cancer, primary care practitioners face one of the most challenging diagnostic and referral issues, given the low prevalence of cancer in the primary care population, the similarity of symptoms to those of much more common conditions, the vagueness of many symptoms and the pressure not to make excessive demands on hard pressed specialist services. But there is a growing awareness of the potential for primary care to improve cancer outcomes. In early diagnosis, for example, there are emerging models which give GPs more flexibility in accessing diagnostic investigation, and guidelines which provide detailed information on ideal risk thresholds to make referrals. This is particularly important in countries where diagnostic intervals are long, and where there are multiple consultations before a cancer is detected.

Once a patient is in treatment or is a survivor, they are likely to make more visits to their GPs for a wide variety of physical and psychosocial reasons. Without a strategy to manage survivorship, many needs of patients may not be met, as described in the US Institute of Medicine report, *From Cancer Patient to Cancer Survivor: Lost in Transition,* which lists four essential components of survivorship care: prevention, surveillance, intervention and coordination.48

There is a particularly pressing need for more evidence on primary care-led survivorship care – made all the more important by the growing number of cancer survivors and the need for much of their care to be transferred to primary care settings. While there are well-identified roles in providing psychosocial support, and coordinating care, less is known about areas requiring more clinically specialised knowledge – for example, in colorectal cancer, little is known about the capacity for primary care to effectively manage treatment side-effects or long-term sequelae.49 There is also variability in primary care, with some practices able to manage complex cancer follow-up regimes, and others having more limited roles.

The GP–patient relationship and easy access to primary care are cited by patients as benefits of primary care-based follow-up, and patients support a greater role for GPs50 – but good communication between GPs and specialists and sufficient knowledge among GPs about follow-up are prerequisites. Survivorship care plans are part of the answer to improving communication among patients and healthcare providers, although more evidence is needed on their optimal use.51,52

The current picture in many countries is that there is much informal follow-up between GPs and cancer survivors and if GPs are to take more responsibility their role needs to be formalised, with appropriate guidelines for the many subgroups of patients,53

including young people and children.54 There are also important considerations about training and remuneration.

Essential requirements

- National cancer plans and guidelines for care pathways must be designed with contributions from family doctors/GPs and must include roles for primary care throughout the cancer journey for all patients.
- GPs must have access to guidelines and risk assessment tools for detecting and preventing cancer. These tools must be integrated into electronic medical records for optimal use and must help to avoid increasing overdiagnosis and overtreatment.
- GPs must have access to timely referral pathways to specialist cancer services that meet the requirements of each cancer type, and must be engaged in diagnosis and treatment decisions. Consideration must be given to open-access provision of common cancer investigations (such as colonoscopy and CT scanning) for GPs; this must be within an evaluative framework that monitors use and outcome of investigations.
- Good communications and efficient administration among the healthcare tiers and among services provided at community level are highly valued by patients, and where the primary care practice must play a pivotal role.
- A coordinated survivorship care plan with a holistic approach including individualised psychosocial care must be in place to ensure continuity of care for all persons affected by cancer, with transition into primary care.
- GPs and their teams must have access to training in appropriate aspects of the cancer journey.
- Patient wishes to have their survivorship and follow-up care where they feel most comfortable – which may often be at a cancer centre – must be respected and new primary care models must promote trust and enable more care to take place in the community.
- High quality research must be carried out into effective models of primary care integration with specialist providers, particular concerning role definition, and communication and relationships among professionals.
- National palliative and primary care frameworks must be integrated to ensure that more people with cancer are identified in a timely manner to benefit from a holistic approach to care as their health declines (see the European Association for Palliative Care (EAPC) Primary Care Reference Group at https://www.eapcnet.eu/eapc-groups/reference/primary-care).

5.2 Nurses

It has become increasingly recognised that nurse practitioners have a key role in ensuring continuity of care for cancer patients as survivorship extends into the primary care setting. However, there are wide differences in cancer nursing provision in Europe at all levels of care. Only a few countries have specialist oncology nurses in cancer units and cancer centres, and few have community nurse specialists for palliative care and support for certain patients, such as men living with side-effects from prostate cancer treatment.

At least one country (Ireland) has developed an oncology education programme for community nurses, while the UK has more than 4,500 Macmillan cancer nurses working in NHS hospitals or the community, some of whom have completed specialist courses in pain and symptom management, or psychological support (see appendix).

Nurses working in the community can be based in variety of settings – primary care practices, outpatient clinics at hospitals and cancer centres, and in community cancer and rehabilitation clinics that are distinct from hospitals. Specialist nurses based at cancer centres can also work partly in the community, helping to support patients at home and in the workplace in conjunction with primary care teams.

In the ERQCC papers that address tumour types at secondary care level, cancer nursing is included in the core multidisciplinary team in every paper, as it is recognised that they can perform a number of roles, from being a navigator for patient care through treatment and follow-up, to representing the patient in MDT meetings, to

a wide spectrum of nursing care that may include advanced practitioner roles. Extending specialist cancer nursing into the community is logical and necessary.

Nurses currently working at primary/community level also have important roles to play in cancer prevention, screening activities and delivering palliative care.

The expert group notes the project, Recognising European Cancer Nursing (RECaN), led by the European Oncology Nursing Society (EONS) and supported by ECCO, as increasing recognition of the value and contribution of cancer nursing across Europe. It is focusing on expert cancer nursing skills, research, education, clinical leadership, strategy and management roles, advocacy and policy development (see http://www.cancernurse.eu/research/recan.html).

Essential requirements

- Cancer nurses must be recognised as core members of multiprofessional teams, and healthcare systems must develop roles for cancer nurse specialists in both secondary and primary/community care settings.
- Healthcare systems must ensure training in cancer care is available to nurses working in primary/community care and that such care is part of a primary care cancer strategy.

5.3 Community pharmacists

Community pharmacists (who number over 400,000 in 160,000 pharmacies in Europe) are primary healthcare professionals with a minimum of 5 years of education and training who practise in the heart of local communities. About 98% of Europeans can access their community pharmacist within 30 minutes and over a third within 5 minutes.55

Much like GPs, community pharmacists establish long-term relationships with their patients and the local communities and help to maintain a sense of normality, familiarity and continuity, as increasing numbers of patients choose to receive their cancer care in the communities most familiar to them. To complement this, community pharmacists across Europe are expanding their traditional repertoire of activities and services to include medication management, pain management services, nutritional advice, digital services, collaboration with other healthcare professionals and providing awareness raising, screening and preventive services.

Medication review (provided in 16 countries) and dedicated services for patients starting a new medication (new medicine services, provided in 8 countries) are services that help to empower patients and increase adherence to therapies. A medication review (type 2)56 is defined as a structured, private consultation between pharmacist and patient focusing on issues of adherence and the safe, effective and rational use of medicines. It also includes over-the-counter (OTC) medications, herbal medications and dietary supplements.57 A new medicine service is similar to medication review, but it is provided to patients starting a new medication to support adherence in the first months of treatment.

Evidence shows that on receiving such a service, adherence increases on average by 10% and polypharmacy, adverse drug reactions (ADRs), interactions, drug-related problems (DRPs) and hospital admissions can be reduced, along with the reduction in costs for health service payers.58,59 In this context, high-risk therapies which could be considered for such interventions include oral anticancer drugs in primary care, which is a challenging area that will require support for community pharmacists.60

Community pharmacists also have the opportunity to provide targeted and opportunistic counselling, screening and referral. The patient may visit the pharmacy for another reason and during the conversation, the pharmacist can advise on dietary and healthy lifestyles, weight management and physical activity, smoking cessation services, vaccination and specific screening services – such as for colorectal cancer.61 Community pharmacists frequently participate in local, regional, national and European level public health campaigns on a variety of topics, including those related to cancer prevention and care.

Yet too often, community pharmacists do not have the full picture of their patients' care. This is often attributable to lack of access or poor interoperability of infrastructure, such as lack of access to the patient's medication record.

In England, a successful pilot programme has demonstrated the value of full-time clinical pharmacists based at primary care practices in providing expert knowledge of medicines and helping to free up time for GPs. These clinical pharmacists could move from roles in community or hospital pharmacy.62

Essential requirements

- Policymakers must recognise that community/primary care pharmacists are strategically placed to take a greater role in cancer prevention, improving cancer care and supporting patients in their communities.
- Community and clinical pharmacy must be integrated further into primary care health services and multiprofessional collaborations.
- Community/primary care pharmacists must have access to a training programme that provides knowledge on safety of oral cancer drugs, adherence, managing adverse drug reactions, drug interactions, nutrition and counselling on cancer prevention.

5.4 Psychosocial/psycho-oncology services

All cancer patients experience some distress, but generally half of cancer patients are significantly distressed.63 Failure to detect cancer distress in cancer patients can contribute to barriers to treatment, decreasing patients' health related quality of life and increasing healthcare costs.64

Psycho-oncologists are professionals who mostly work in cancer centres to ensure that psychosocial distress65 and other psychological disorders and psychosocial needs are identified by screening throughout the disease continuum; promote effective communication between patients, family members and healthcare professionals; and support patients and family members to cope with multifaceted disease effects.

Psychosocial interventions are effective in improving outcomes66 and also cost-effective67 and will become increasingly important according to the growing population of cancer patients and survivors. Access to these interventions from appropriate professionals at primary and community level will be needed, as well as in hospital outpatient departments.

There has been more than 40 years of research on screening for depression and distress in primary care but most studies report pitfalls such as relying on unassisted judgement without infrastructural support and using overly complex scales; approaches developed in psycho-oncology must be applied and all primary care providers must be primed to deliver them.68

Essential requirements

- Standardised routine cancer distress screening must be continued in primary care and be performed by electronic means wherever possible.69
- All cancer patients and survivors must have access in primary care to psychosocial interventions in all phases of the cancer disease trajectory delivered by psychosocial workers and consultants (e.g. psycho-oncology professionals) appropriate to their needs. Underserved patient groups (e.g. older people, rural populations) need special attention.
- Psychosocial social interventions in primary care must be comprehensive, drawing on a variety of techniques and on an eclectic methodological mix to meet various needs of cancer patients and survivors and to engage them in shared decision-making.70
- Psychosocial rehabilitation must be prioritised in national cancer control plans and cancer survivorship must be recognised as a distinct clinical category that includes psycho-oncology.

5.5 Occupational therapists

The primary goal of occupational therapy is to enable people to participate in meaningful activities, such as return to work and other daily living activities. People with cancer or survivors can benefit from occupational therapy assessment and rehabilitation throughout their cancer journey. Occupational therapists provide assessment, intervention and support during, between and after treatment and, if necessary, care at the end of life.71,72

Caregivers can also benefit from occupational therapy through support, education and training to reduce risk of injury and negative experiences, and to cope with end of life care and bereavement.73

Occupational therapy interventions can not only reduce the burden of symptoms on activity and achieve better quality of life but also address physical, social, emotional and spiritual needs.74 They can reduce demand on primary care by resolving functional issues that are the root cause of multiple contacts with the practice. Practitioners confirm there is broad scope for both physical and psychosocial interventions.75,76

Key elements of occupational therapy are:

- Promoting engagement in valued activities and occupations (e.g. vocational and leisure)
- Optimising independence in daily living activities
- Providing interventions including education, rehabilitation, retraining in daily living activities, environmental modification and prescription of equipment to support recovery and adaptation
- Educating on symptom management to improve functional status, e.g. breathlessness, comfort, pressure care, cancer-related fatigue, pain, cognition impairment, sensory and neurological disturbances and upper limb dysfunction.

Essential requirements

- Occupational therapy enables engagement in the workplace and must be an integral part of the multidisciplinary primary or social care team.
- Remuneration for occupational therapy services, such as through insurance, must be provided for patients.

5.6 Palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems – physical, psychosocial and spiritual.77

There is an increasing need for palliative care throughout the disease trajectory, especially for patients with advanced or metastatic cancer to manage distressing clinical complications and symptoms and to improve the quality of life of patients and their families.78,79,80

Primary care professionals can lead palliative care in the community, in collaboration with secondary care and specialist palliative care services/teams.81 These professionals must be provided with high-quality training and be adequately resourced to do so, and can help address stigma about palliative care to increase its take-up.

Essential requirements

- There must be early identification of people with life-threatening cancer and with potential palliative care needs.82
- Assessment of holistic needs must be carried out, including pain and symptom management.
- There must be multiprofessional teamwork within primary care, in collaboration with oncology and specialist palliative care services.83

- Good quality communication with patients and caregivers is needed to plan future care, taking into account the burden of multimorbidity, frailty and polypharmacy,84 particularly in older people and in deprived areas.
- Care must meet the complex needs of vulnerable and marginalised populations to tackle health inequalities (e.g. by funding outreach programmes to help often excluded groups such as those with mental health problems, learning disabilities, and people experiencing homelessness to access general practice).
- Pain relief medications (including opioids) must be available and accessible in the community.[34,85,86]
- Policymakers must advocate mechanisms of payment for primary care professionals who facilitate multiprofessional teamwork and patient review.
- Public awareness must be raised of the benefit of having palliative and oncology care integrated in the course of cancer treatment.

5.7 Carers

Carers are people who provide unpaid care to someone with a chronic illness, disability or other long-lasting health or care need, outside a professional or formal framework. According to a white paper by the European Cancer Patient Coalition and Eurocarers, carers already provide 80% of care in Europe but the increasing burden of chronic diseases such as cancer mean that urgent policy action is needed to ensure the sustainability of caregiving.87

It is said in the paper that policymakers must look beyond traditional healthcare pathways and employment policies, and acknowledge that carers continue to provide a substantial portion of care across Europe. While people with cancer are identified through diagnosis, cancer carers often remain largely anonymous despite the fundamental role they play in the healthcare pathway.

The paper also highlights that aggressive and long-lasting forms of cancer impart a particular burden on carers and requires a robust framework to support their role. Without carers, people with cancer would miss out on an invaluable resource and health systems would be unable to sustain the burden of care.

There are recent studies that are contributing to research on cancer carers and the ways they can be supported. For example:

- Psychosocial interventions that specifically target caregivers' coping and emotion regulation skills, family functioning, and self-care are endemic to the preservation of the health and wellbeing of this vulnerable population88
- Social workers' awareness of the challenging situations of cancer carers and the potential impact this has on ability to provide care to the patient89
- The needs of carers have to be legitimised to ensure primary care staff are proactive in their approach and carers are empowered to use the support available.90

Essential requirements

- Policymakers must formally recognise the role of carers and provide appropriate welfare programmes, including paid carer leave, flexible work arrangements, financial compensation and pension rights.
- Carers must have access to programmes including information, training and psychological support, and must be included in a patient's care team.
- Carers must be encouraged to identify themselves as carers and take part in support programmes, given that many do not identify with the term.91

- At European level, governments must adopt the New Start initiative for work-life balance for parents and carers proposed by the European Commission and supported by the European Parliament as part of the European Pillar of Social Rights, including the right to 5 days of leave paid at the minimum level of sick leave, and other European programmes that affect carers.

Integration with hospital care

To achieve the best outcomes, integration of primary care with hospital cancer care must include access to state-of-the-art diagnosis and treatment. In broad terms, the characteristics of best practice in cancer control are well recognised. They are programmes on prevention, lifestyle changes and screening; prompt access to diagnostic testing; prompt access to excellent specialised multidisciplinary care (including supportive, survivorship and palliative care); programmes to promote access for disadvantaged groups; and research and innovation.

Many specialties and disciplines are essential to the delivery of care across the spectrum of cancer control and here the expert group emphasises the importance of high quality MDTs that plan the management of every cancer patient, and which are covered in the tumour specific ERQCC papers. The core MDT includes all the appropriate diagnostic and therapeutic specialties that relate to a particular cancer.

Surgical, medical and radiation oncologists are members of every core MDT; diagnostics specialists in imaging and pathology are also essential, as are nurses. Equally important where appropriate are the many specialties which, although not solely concerned with cancer, contribute a great deal to the best practice in cancer diagnosis and treatment as part of core and extended MDTs. They include respiratory physicians for lung cancer patients, gastroenterologists for gastrointestinal cancer patients, gynaecologists, urologists, head and neck surgeons, haematologists and many others, each contributing to their relevant cancer site.

Specialist care in hospital includes the planning and management of complications of therapy which will involve many other specialists such as endocrinologists, fertility specialists, neurologists, geriatricians, psychologists and psychiatrists and specialists from all of the organ-specific specialties that are relevant to long-term toxicities and other survivorship issues.

6 Other professionals

6.1 Geriatricians

In the ERQCC papers on individual cancer types, a common member of the extended MDT is a geriatric oncologist, who is most likely to be a medical oncologist with an interest in older people. As most cancers are primarily diseases of older people, there are often frailties and co-morbidities that must be taken into account in treatment decisions and in respecting the wishes of patients.92 But guidelines, for example in older men with prostate cancer, state that treatment decisions in older people should not be based on chronological age but on general health and patient preference.93

Geriatric oncologists coordinate recommendations to other specialists about the need for personalised treatment for older patients with increased vulnerability;94,95 and increasingly, such knowledge will be applied in primary care by geriatricians, GPs and other professionals. Key requirements are:

- All older patients (70+) must be screened with a quick, simple frailty screening tool, such as the adapted Geriatric-8 (G8) screening tool 96 or similar tools
- Frail and disabled patients must undergo a geriatric assessment.97 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-Cog98 is essential. A geriatrician or a geriatric psychiatrist or neurologist would preferably be involved with impaired patients.

6.2 Dentists

Dentists have a vital role to play in ensuring oral cancers are detected early and patients are informed about risk factors.99 They also must be involved in dental problems that arise during treatment such as from chemotherapy.100

6.3 Other professionals

There are many other professionals who must be available to provide integrated care (and are known as allied health professionals in the UK). They include:

- Physiotherapists101
- Nutritionists/dietitians102
- Lymphoedema103 and stoma specialists104
- Speech and language therapists105
- Podiatrists106
- Psychosexual counsellors.107

7 Conclusion

The information presented in this paper provides an overview of the challenges and requirements for considering better integration of primary care professionals and settings in cancer care. The ERQCC expert group is aware that it is not possible to propose a **'**one size fits all**'** system for all countries, and has taken a practical approach to point to research and projects that can guide policymaking. Primary care integration is in its early stages and faces many obstacles, but we urge that access to multiprofessional, specialised care is guaranteed to all cancer patients throughout their journey.

Conflict of interest statement

The authors declare no conflicts of interest for this paper.

Appendix – Projects, tools and other resources

The ERQCC expert group welcomes contributions to this list, which in this first paper is a brief snapshot.

Primary care

Diagnosis and management

- The Royal College of General Practitioners (RCGP) in the UK has a range of cancer toolkits for primary care including on prevention, screening and referral; consequences of cancer treatment; and quality improvement in early diagnosis. See http://www.rcgp.org.uk/cancer.
- Macmillan's support for primary care incudes resources for early diagnosis, treatment and recovery, and end of life care. See https://www.macmillan.org.uk/about-us/health-professionals/resources/resources-for-gps.html.
- The Accelerate, Coordinate, Evaluate (ACE) programme is an early diagnosis initiative supported by the National Health Service (NHS) England, Cancer Research UK (CRUK) and Macmillan Cancer Support. See http://www.cancerresearchuk.org/health-professional/early-diagnosis-activities/ace-programme. It was formed to help improve England's cancer survival rates by generating evidence on how best to configure diagnostic pathways to drive a shift from late to early cancer at diagnosis, reduce the number of cancers diagnosed as an emergency and improve patient experience. 108
- Denmark has developed a 'three-legged' strategy for diagnosing cancer, which includes urgent referral pathways for symptoms suspicious of a specific cancer, urgent referral to diagnostic centres for evaluation of patients with nonspecific, serious symptoms, and fast access to 'no-yes' clinics for cancer investigations for those patients with common symptoms in whom the diagnosis of cancer should not be missed.109
- The European Guide on Quality Improvement in Comprehensive Cancer Control presents examples of primary and community care integration, such as the evidence-based Orkdal model in Norway.[3]

Audit

The first National Audit of Cancer Diagnosis in Primary Care in England was undertaken in 2009–2010 on about 17,000 patients in 439 primary care practices, finding that where GPs deemed diagnostic delays to have occurred (22% of cases), patient, clinician or system factors were responsible in 26%, 28%, and 34% of instances. An enhancement of the audit was conducted in 2016/17, which found that 74% of patients were referred to a specialist after only one or two consultations.110

Community pharmacy

- Multiprofessional collaborations to improve care by sharing medication records include the Summary Care Record in England,111 which is a summary of the GP patient record and which can be shared with other healthcare professionals. A pharmacy-managed medication record, Dossier Pharmaceutique, is shared among pharmacists in Belgium and among pharmacists and hospital physicians in France. Another example of multidisciplinary collaboration which could improve cancer care includes the use of 'pharmacotherapy meetings' (PTMs) in the Netherlands, where general practitioners and pharmacists set common goals on how to optimise pharmacotherapy.112
- Germany provides community pharmacies with the information required to manage patients receiving oral cancer drugs, which includes adverse drug reactions (ADRs) and advice. Training is provided to all pharmacies working with cancer patients. The German model has been taken up by the European Society of Oncology Pharmacy under the EPIC project to develop similar models in other European countries, and has been launched in Slovenia and Estonia with others planned. The main aim of EPIC is to provide healthcare professionals with the right information to manage patients receiving oral

chemotherapy from hospital or community pharmacies. See: http://www.esop.li/epic.php.

- In the Netherlands dispensing of all cancer drugs has been centralised in hospital pharmacies, but community pharmacies can access the dispensing data if the patient has given permission through a national switchboard. The hospital pharmacy can use the switchboard to see the dispensing data of the community pharmacy, when the patient has given permission.

Nursing and rehabilitation

- A number of locations in England have established nurse-led clinics in primary care practices to care for prostate cancer patients, such as in Manchester. Patients who have received treatment at the Christie cancer centre are transferred to the community service when appropriate; for radiotherapy patients this happens as soon as treatment is completed. More than 1,000 patients have been moved into community based follow-up clinics and clinics have been set up in 6 locations, with more planned. This has freed up over 1,500 hospital appointments. A majority of men were able to self-manage when supported with the right advice.113
- Ireland has an oncology education programme for community nurses that was set up in response to the country's national cancer strategy of 2006. It aims to provide nurses with the skills to assess and manage patients living with cancer at home, develop an integrated way of working between acute and primary care sectors, and transfer appropriate aspects of cancer to the primary care setting. A Policies, Procedures and Resource Book has been developed to support the programme.114
- A community oncology clinic in the US created an advanced practice nurse (APN)-led survivorship programme using the concept of 'seasons of survival' as a guide. A paper on the project reports that survivorship care, when based on a more expansive definition of survivorship as beginning at the time of diagnosis, encompasses holistic nursing and multidisciplinary care.115
- The Cancer Rehabilitation Centre in Stockholm has a multidisciplinary team comprising an occupational therapist, social worker, physiotherapist, dietician, psychologist, neuropsychologist, psychotherapist, nurse and doctor. There are also specialist teams for pelvic cancer rehabilitation, comprising nurses specialising in urology, pain, bowel problems, gynaecology and sexology, and for follow-up after childhood cancer, with a nurse, physician, neuropsychologist and counsellor. See: http://rehabcancer.se. Sweden has similar cancer rehab units in other regions.
- The Onc'Idec platform in the Auvergne region in France coordinates private practice nurses to ensure that patients are supported in the transition from hospital to home.116
- Details of a number of community cancer nursing projects under the Bridging Cancer Care initiative in Central and Eastern Europe are given in a paper.117

Psychosocial/psycho-oncology services

- The European Guide on Quality Improvement in Comprehensive Cancer Control has case studies from European countries that include policy recommendations that address psychosocial needs (e.g. cancer distress, fear of cancer recurrence) of cancer patients and survivors in primary care.[3]

Occupational therapy

- A book that is said to be the only one on occupational therapy in oncology and palliative care is currently in its 2nd edition.118 It includes chapters on the challenges faced by occupational therapists, therapy for managing anxiety, breathlessness and fatigue, and measuring outcomes.
- A report from the UK's Royal College of Occupational Therapists has highlighted that early access to occupational therapy for people with mental ill health could ensure that they have the best long-term health and social care outcomes.119

Palliative care

- The European Association for Palliative Care (EAPC) has established a reference group for primary care (https://www.eapcnet.eu/eapc-groups/reference/primary-care) and published a toolkit for developing palliative care in the community, available in English, French, German and Italian.120,41
- The World Health Organization has published a guide to integrating palliative care and symptom relief into primary healthcare, noting that, globally, inequality of access to palliative care is one of the greatest health disparities.[42]

Carers

- France's national cancer plan (2014-2019) included an investment of €1.5 billion to provide respite facilities to family carers.121 France has also passed a law granting carers new employment rights.122

- Eurocarers has an essential care and cancer toolkit at: http://www.eurocarers-cancer-toolkit.eu/coping-with-caregiving.

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