

# **European Guide on Quality Improvement in Comprehensive Cancer Control**

Tit Albreht, Régine Kiasuwa and Marc Van den Bulcke



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European Guide on Quality Improvement in Comprehensive Cancer Control

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*The Editorial Team*



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# List of abbreviations

<b>ASCO</b>	American Society of Clinical Oncology
<b>AYA</b>	adolescents and young adult
<b>CanCon</b>	Cancer Control
<b>CAPO</b>	Canadian Association of Psychosocial Oncology
<b>CCC</b>	Comprehensive Cancer Centres
<b>CCCN</b>	Comprehensive Cancer Care Network
<b>CEA</b>	carcino-embryonic antigen
<b>CRC</b>	Colorectal cancer
<b>DHA</b>	Danish Health Authority
<b>DKH</b>	German Cancer Aid
<b>ECAC</b>	European Code Against Cancer
<b>ECCO</b>	European Cancer Organisation
<b>ECPC</b>	European Cancer Patient Coalition
<b>EFTA</b>	European Free Trade Association
<b>EJC</b>	European Journal of Cancer
<b>ENCCA</b>	European network for cancer research in children and adolescents
<b>EORTC</b>	European Organisation for Research in Therapies against Cancer
<b>EPAAC</b>	European Partnership for Action Against Cancer
<b>EPRS</b>	Electronic patient records systems
<b>ERSPC</b>	European Randomised Study of Prostate Cancer Screening
<b>ESMO</b>	European Society of Molecular Oncology
<b>ESO</b>	European School of Oncology
<b>ESSM</b>	European Schools for Screening Management
<b>ESSO</b>	European Society for Surgical Oncology
<b>ESTRO</b>	European Society for Radiotherapy and Oncology
<b>EUNICE</b>	European Network for Information on Cancer
<b>EURECCA</b>	European Registration of cancer care
<b>EUROCOURSE</b>	Europe Against Cancer: Optimisation of the Use of Registries for Scientific Excellence in research
<b>EUSANH</b>	European Science Advisory Network for Health
<b>EWAC</b>	European Week Against Cancer
<b>FISABIO</b>	Fundación para el Fomento de la Investigación Sanitaria y Biomédica (FISABIO) de la Comunitat Valenciana
<b>FIT</b>	Immunochemical faecal blood test
<b>FOB</b>	Faecal occult blood
<b>FOBT</b>	Faecal occult blood test
<b>GCC</b>	Guide Coordination Committee
<b>GDP</b>	Gross domestic product
<b>GP</b>	General Practitioner
<b>HCRA</b>	Hunter Cancer Research Alliance
<b>HERO</b>	Health Economics in Radiation Oncology group
<b>HPV</b>	Human papillomavirus

<b>IARC</b>	International Agency for Research on Cancer
<b>ICER</b>	Incremental cost-effectiveness ratio
<b>ICP</b>	integrated care pathways
<b>IOM</b>	Institute of Medicine
<b>JA</b>	Joint Action
<b>JARC</b>	Joint Action on Rare Cancers
<b>JCO</b>	Journal of Clinical Oncology
<b>JRC</b>	European Commission, Directorate General Joint Research Center
<b>LCDT</b>	Low-dose computerized tomography
<b>MDT</b>	Multidisciplinary teams
<b>MMCI</b>	Masaryk Memorial Cancer Institute
<b>MoH</b>	Ministries of Health
<b>NBH</b>	National Board of Health
<b>NCCP</b>	National Cancer Control Plan
<b>NCD</b>	Non-communicable disease
<b>NCI</b>	National Cancer Institute
<b>NCSI</b>	National Cancer Survivorship Initiative
<b>NGO</b>	Non-Governmental Organisation
<b>NGS</b>	Next Generation Sequencing
<b>NICE</b>	National Institute for Health and Care excellence
<b>NIVEL</b>	The Netherlands Institute for Health Services Research
<b>OECI</b>	Organization of European Cancer Institutes
<b>ONS</b>	Osservatorio Nazionale Screening, National Centre for Screening Monitoring, Italy
<b>PCP</b>	Primary care providers
<b>PROMS</b>	Patients reported outcome measures
<b>PSA</b>	Prostate specific antigen
<b>PSOC</b>	Psychosocial care
<b>QA</b>	Quality assurance
<b>QALY</b>	Quality adjusted life-years
<b>QI</b>	Quality Improvement
<b>QoL</b>	Quality of life
<b>RCT</b>	Randomized controlled trial
<b>RTW</b>	Retrun to work
<b>SCP</b>	Survivorship Care Plan
<b>SIRIC</b>	Integrated Cancer Research Sites
<b>SOP</b>	Standard operating procedures
<b>TMG</b>	Tumor management groups
<b>UICC</b>	International Union Against Cancer
<b>WHO</b>	World Health Organisation
<b>WHO-CHOICE</b>	World Health Organisation, Cost effectiveness and strategic planning

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# Foreword

This Guide aims to help to reduce not only the cancer burden throughout the EU but also the inequalities in cancer control and care that exist between Member States. It is the culmination of years of coordinated work in an EU-funded project, CanCon. We hope that everyone involved in providing cancer care will consider put this Guide and consider implementing its suggestions.

Cancer exerts a heavy burden on European societies and on health care systems, exacerbated by our ageing populations. In 2012 alone, 2.6 million European Union citizens were newly diagnosed with some form of cancer and the estimated total number of cancer deaths in the European Union in 2012 was 1.26 million. Given today's incidence rates, we expect that 1 in 3 men and 1 in 4 women in the European Union will be directly affected by cancer before reaching 75 years of age.

Cancer is, and must remain, a high priority at all levels. For more than 30 years, the European Commission has been working to help address the cancer challenge and remains highly committed to contributing to the constant improvement of cancer prevention and care.

For these reasons, the Commission launched and supported the Joint Action on Comprehensive Cancer Control (CanCon). This Joint Action had two main objectives: (i) to identify key elements and quality standards for cancer control in Europe to help reduce disparities and inequalities; and (ii) to facilitate co-operation among Member States. This includes the exchange of best practices as well as identifying and defining key elements to ensure optimal and comprehensive cancer care.

One of the most important Work Packages in CanCon has been dedicated to coordinating the Guide, which is the single most important outcome of the project. The Guide is a coherent, patient-centered document and a key strategic tool for governments and policy makers. The core chapters of the Guide focus on integrated cancer control, community-based post-oncological care, cancer survivorship and rehabilitation – from treatment to recovery and beyond – and population-based screening programmes.

Over the last decade, diagnosis and treatment of cancer have become increasingly costly, inter alia as a result of rapid advances in technology and drug development. At national level, a key requirement for successful cancer management is an integrated approach to all the dimensions of cancer care. The CanCon Guide provides a unique instrument to do this in a high qualitative manner, helping to reduce inequalities between Member States.

Together with the feedback received by all the stakeholders on the scope of this Guide, the recommendations provided in this report will help ensure that the Guide takes crucial aspects of care into account while respecting the existing organization of care within each country.

I hope that those in charge of caring for cancer patients throughout the Member States will consider the contents of this Guide. The Commission stands ready to support the implementation process, particularly through its Cancer Committee and using other support instruments.

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# Part I



# Introduction

Tit Albreht and Marc Van den Bulcke

## History

Thanks to the forward thinking and wisdom of both the experts in the field of cancer and the European policy-makers of the time, the European Council adopted the launch of the Europe Against Cancer programme in June 1985 at its meeting in Milan. The choice of the moment and the venue were not accidental. They coincided with the belief that European concerted action in the field of cancer was necessary, as proposed by the key cancer experts of the time, and Milan, with its strong traditions and institutions in cancer research, was a well-chosen venue.

On 28 December 1985, the European Commission passed a proposal for a Council resolution on a programme of action for the European Communities on cancer prevention (1). In its annex, this proposal outlined the entire text of the programme, which had six important objectives:

- to halt the increase of cancer in the Community leading to a downward trend in both incidence and mortality from the disease;
- to decrease the potential years of life lost from cancer;
- to establish health strategies for those factors to which cancer is attributed;
- to improve the data available on cancer incidence and mortality and the data for epidemiological studies for monitoring the health of specific groups of the population and for identifying new or unforeseen risk factors for cancer;
- to facilitate cooperation at Community level and exchange of information relating to programmes for population screening and treatment in order to improve their performance; and
- to collaborate with international and national organizations in the field of cancer prevention to the attainment of these objectives and the application of the results of cancer research.

It is clear that these objectives are still currently of importance and that they still belong to the core of any serious cancer plan and/or strategy. These efforts, together with the commitment to work on cancer prevention jointly with the World Health Organization (WHO) and the International Agency for Research on Cancer (IARC), meant that there would be political support for broad activities directed at cancer prevention and improved cancer control.

The activities of the programme were split into action plans, which were operational instruments directed at focused implementation of specific prioritized activities. It is interesting to note the report on the second action plan, reporting on the period 1990–1994 (the first being for the period 1986–1989) (2). It was published on 18 July 1995 and contained a detailed elaboration of the activities carried out in the five-year period. The implementation was centred on the following key topics:

- prevention of tobacco consumption
- studies and preventive measures on diet (including alcohol)
- campaign against carcinogenic agents
- information for the public on preventive measures
- health education: preventive measures
- cancer training measures for health professionals
- cancer screening
- studies and projects related to quality assurance in the cancer treatment
- cancer research

The programme was managed by three levels of committee: the Advisory Committee, the Cancer Expert Committee and national coordination committees. There was also intense collaboration with different nongovernmental organizations and international nongovernmental organizations (WHO, the European Organisation for Research in Therapies against Cancer, the European School of Oncology and the International Union Against Cancer). Prioritization included three main fields with 38 actions in three main tracks: cancer prevention, early detection and screening, and quality assurance in cancer therapies. Two topics that were particularly important in that action plan are still pertinent today: cancer prevention including promotion, focusing on reducing the burden of tobacco, and the promotion of the European Code Against Cancer.

Europe Against Cancer continued through a period of almost 20 years, with its programme carried out through action plans each adopted for periods of 5 years. This way, priorities could be modified and adjusted according to the developing needs of the Member States of the European Union (EU) and aligned along the policies adopted at the level of the European Commission and the European Parliament.

It was a pity that this programme stopped in 2003, just one year short of the biggest enlargement of the EU in its history.

## Revival of cancer as one of the priority areas of the EU health policies

Soon after the closure of Europe Against Cancer, it became evident that it would be beneficial to Member States and to the EU's policies if some sort of collaboration on cancer could be re-established. In the course of the preparation of the trio of presidencies to the Council of the European Union 2007–2008 (Germany, Portugal, Slovenia), cancer was proposed as the main health topic of Slovenia's Presidency. However, it was already within Portugal's Presidency when cancer discussions were launched again.

The main conference of Slovenia's Presidency focused on four key areas: health promotion, early detection and screening, integrated care and cancer research. These were identified as priority areas with the biggest impact on the potential success of European policies in the field of cancer control.

There were several tangible outputs of Slovenia's Presidency:

- publication of the book *Responding to the challenge of cancer in Europe (3)* as a comprehensive overview and mapping of all the dimensions of managing cancer prevention, control and care in Europe;
- production of the policy summary *Fighting Against Cancer Today*, which was an overview of the achievements and challenges during the previous 18 months and for the future; and
- formation of recommendations on the future work on cancer in the framework of the European health policies.

## Recent activities

As the result of the efforts put into the discussions on cancer in 2007 and 2008, in 2009 the decision matured that there would be the formation of the European Partnership for Action Against Cancer (EPAAC) with a clear commitment of both the European Commission and the Member States. The format of a partnership appeared to be best fitted for this kind of joint activity. This set the scene and the base for the launch of the first Joint Action on Cancer, called EPAAC, the same as the partnership itself.

The definition of the topics of EPAAC was initially motivated by the priorities of the European Commission but finalized in an open exchange process. The main elements were clearly:

- comprehensiveness of the entire span of the cancer-related issues;
- exploring the situation with the national cancer plans in Member States;
- finding a solution for the European cancer information system; and
- providing a broad platform for discussion on cancer-related topics and issues.

EPAAC clearly evolved its activities around six different topics:

- 1 Health promotion and primary prevention against cancer
- 2 Early detection and screening for cancer with a clear focus on the quality assurance of these processes
- 3 Integrated cancer care
- 4 Research in cancer
- 5 Cancer data and information, development of the European Cancer Information System
- 6 Development of the national cancer control plans or strategies

There was careful elaboration of all the six topical areas in EPAAC and it resulted in a number of technical deliverables, which made important progress in each of the fields they were dealing with, in particular:

- revival of the European Week Against Cancer, with re-established annual events in raising awareness against cancer in Member States;
- gaming used in promoting knowledge and awareness about lifestyle issues related to cancer among young people;
- establishment of quality criteria and standards for the development of high-quality screening programmes for cancer;
- multidisciplinary and networking of expert institutions in cancer care increased and elaborated as important issues in the development of modern cancer care;
- framework for future research work in the field of cancer research at the level of the EU;
- establishment of the European Cancer Information System, support to the European Network of Cancer Registries and securing their domicile at the Joint Research Centre of the European Commission at ISPRA in Italy; and
- analysis of the developments in the preparation and adoption of national cancer control plans and setting up guidelines for their future development.

The legacy of this first joint action, EPAAC, included:

- a book (Boosting innovation and cooperation in European cancer control: key findings from the European Partnership for Action Against Cancer (4) that provided a comprehensive and complete summary of the work elaborated in each of the work packages of the project;
- a book (European guide for quality national cancer control programmes (5) that provided a guide for policy-makers and their advisers on how to approach and structure a national cancer plan/strategy/programme; and
- a policy platform through open fora that ensured exchange of experiences and work on the selected topics in quality control directly through the active participation of the Member State representatives and relevant international and national stakeholders.

## Setting up of CanCon

In 2013, the European Commission decided to conclude the work of EPAAC as a partnership and give more emphasis to comprehensive cancer control with a focus on care. As many issues arise from care itself, where Member States face different and numerous challenges, it seemed a good setting to accommodate at least some of the potential solutions. This meant that the main issues in the next Joint Action on Cancer would be related to cancer care and to a lesser degree on prevention. The consultation process in the preparation of the programme resulted in the topics being decided based on the following aspects:

- priorities of the European Commission
- priorities of the Member States
- challenges related to cancer in Europe

The setup of the new Joint Action on Cancer (CanCon) was to be similar to the previous one, with four prioritized topics:

- comprehensive cancer control networks (CCCNs)
- community cancer care and after-care in cancer
- survivorship
- screening guidance

These topics were accepted by the Member States and lead institutions were willing to start building work on each of these topics together with interested partners from other Member States. As the structure of the Joint Action changed compared with EPAAC, it was necessary to set up a venue for Member States to discuss their common and burning priorities. This was done by developing a Member State Platform. Five policy topics were selected in direct voting of Member States:

- national cancer control programmes/plans/strategies
- public health genomics and cancer
- effectiveness of cancer prevention
- disinvestment in cancer
- social inequalities in cancer

The first four topics were dealt with through work packages (see Chapters 4–7) whereas the policy topics, leading to policy papers, were elaborated in interaction of the lead Member States with the experts, who would publically tender for this task. Given the different methodologies and preparation processes, the policy papers are not presented or included in this volume but will be published in a separate manner with the focus on policy use by Member States.

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# European Guide on Quality Improvement in Comprehensive Cancer Control

Context, summary recommendations and appraisal

Josep Maria Borrás and Mark Dobrow

## Introduction

Cancer control is a complex and challenging topic. Many people are affected directly or indirectly by the health effects of cancer and many people directly or indirectly participate in cancer control. While there are many individual interactions between patients and a wide range of formal and informal care providers through the delivery of care, comprehensive cancer control further encapsulates all of the additional resources and activities that contribute to the governance, financing and management of cancer services and systems.

Over time, incidence and prevalence have been increasing for most cancers through a number of factors, including ageing populations and increasingly more effective treatment interventions. Alongside this, unacceptable cancer inequities exist both between and within European countries. The evolving shift in several types of tumour to cancer as a chronic disease requires health systems to examine better ways to organize and structure their investments and efforts to provide effective, comprehensive and equitable cancer control that meets the various needs of cancer patients along the extended trajectory of their experience with the disease. The European experience suggests that while most key cancer control challenges and issues are universally faced, approaches to address them successfully have both common and country-specific elements and consequently guidance requires a contextual lens. CanCon provides an important opportunity to examine these varied approaches to improve cancer control amid the mix of prevailing health system contexts and experiences with the intention of supporting the operationalization and application of evidence-informed guidance to specific settings.

This chapter will first situate the Guide within the context of other European initiatives by documenting a few examples that have been promoted or supported by different stakeholders in order to improve cancer control; it will then go on to discuss the growing need for system-level guidance and the rationale for the Guide's four areas of focus. An overview of the Guide's recommendations are given and then appraised before concluding with an assessment of future opportunities for comprehensive cancer control.

## European initiatives to improve cancer control

One of the most relevant changes in cancer control strategy has been the consolidation of the European-level perspective of many initiatives since the Europe Against Cancer programme initiated in 1985 by the European Council and a Committee of Cancer Experts. From an initial focus on information systems, primary prevention and screening, cancer control programmes and activities have extended their coverage to include cancer care, particularly regarding psycho-oncology, quality-of-life issues and palliative care, as well as the need to have population-based data from cancer registries in order to assess the quality of cancer care outcomes. Although not all countries have yet managed to institute all programme elements, the publication of successive EUROCARE results from the mid-1990s until EUROCARE V, which compare the relative survival by country and tumour site, has been a landmark to this end, associating the possible role of cancer care quality, organization and delivery with the remarkable differences observed among European countries (1,2). Thanks to the standardized collection of data, the extent to which these variations could be attributed to methodological differences in data collection has been minimized.

The organization of cancer care could be viewed as a laboratory of many organizational changes in health care at micro- (clinical management), meso- (health care organization) and macro- (health system) levels. A clinical management example is the conceptualization and extensive application of multidisciplinary teams and the evaluation of their impact on health outcomes (3,4). From a health system level, an example could be the progressive acknowledgement and wide adoption of the need to assess the delivery of cancer care across its continuum through the national cancer plan perspective. Since the landmark example given by the Calman-Hine Report, with a proposal of a reorganization of the provision of care in England and Wales in order to improve the outcomes for patients among different measures, cancer control programmes have adopted progressively a broader perspective along the continuum in different EU countries (5). In this respect, the Institute of Medicine published a report in 1999 (Ensuring quality cancer care) that considered the existing gap between ideal quality of cancer care that could be provided to patients and the real-life care received; the proposed recommendations included improved access to hospitals with extensive experience in complex procedures, development of evidence-based guidelines, improved end-of-life care and monitoring of the quality of cancer care, among others (6). Although progress has been made in these recommendations since the publication of the report (7), it is notable that the same institution felt it necessary to re-assess the situation 15 years later and then reviewed the recommendations with more emphasis on survivorship, accessible and affordable care, translation of evidence into clinical practice and the development of the capacity of a learning health care system in the field of oncology (8). In summary, the core of many activities carried out by governments, scientific societies and patient organizations is how to deal with the challenges posed by the evolution of the changing needs of patients, the improvements required in access and quality of cancer care and the organizational requirements to cope with innovations in cancer screening and care. This growing involvement of stakeholders in cancer control activities has also

taken place at the European level, in close interaction with EU Commission initiatives and national cancer control plans. As a framework to the recommendations of the CanCon project, a brief review of the initiatives set up at EU level will be presented to outline the state of the art situation and its alignment with CanCon efforts.

### **Consensus on the evidence for primary prevention and screening: the European Code Against Cancer**

The European Code Against Cancer has reached its third edition, using a consistent approach throughout, combining evidence-based review of the scientific literature about primary prevention and screening with the publication of a list of specific and clear recommendations for the general population about what to do in order to prevent cancer. The reviews of each recommendation have been published in *Cancer Epidemiology* (9) jointly with the list of recommendations. It is worth highlighting the effort to build a consensus about aspects of prevention and screening, such as dietary recommendations or breast screening, which have been surrounded by controversies from different perspectives since the first version of the European Code. There is wide consensus about the relevance and usefulness of this approach as the scientific background for creating messages aimed at achieving effective cancer prevention.

### **Reference networks for cancer care at EU level: the case for rare cancers**

Rare cancers have generated strong interest at the EU level, as shown by different EU-funded projects. In a combined multistakeholder initiative, the European Society for Medical Oncology led Rare Cancer Europe, which includes support for actions at the EU level to build reference centres, disseminate high-quality clinical guidelines and address obstacles for patients to access appropriate therapies (10). This is the approach adopted in the EU policy of developing European reference networks, such as the Directive on Cross Border Health Care, and in course of implementation with applications for rare cancers for both adults and children. This offers a framework for organizing access to knowledge and care, when required, for clinical services with high-quality experience in dealing with the diagnosis and treatment of this group of rare cancers. The new Joint Action on Rare Cancers, which begins its three-year period of work at the end of 2016, involves country-specific cancer plans, cancer registries, scientific societies and patient organizations and will deliberate on the opportunities and challenges for these groups of cancer. This collaboration perfectly illustrates the potential advantages of a European-level perspective. It offers an opportunity to explore the issues of coordination of care among different partners, levels and specialties that is at the core of any improvement in the continuum of care. It is also worth noting the importance of patient associations in this field, as well as in other areas of cancer control, which have been instrumental in the development of several European projects that have paved the way for initiatives such as the European reference networks.

## Initiatives by scientific societies: building blocks for cancer control policy at the EU level

Policy and organizational aspects of cancer care have been highlighted by the innovative character of cancer care fuelled by research progress, the need for coordination of different specialists in a multidisciplinary approach to the diagnosis and treatment of cancer patients as well as by the challenges posed by the organization of care involving different levels of care and transitions among them (11). All these factors should be combined with the increasing costs of cancer care in order to assess the relevance of involving all stakeholders in order to agree on the way ahead. Many actors take part with different degrees of influence, but there is no question about the essential role that scientific societies should play in the development of cancer control policy, in parallel with the essential contribution of patient associations. Indeed, scientific societies have shown their willingness through different initiatives, which can be grouped under the global framework of oncology policy. Some examples will be briefly summarized in order to highlight their relevance for European cancer control.

EURECCA is an initiative of the European Society for Surgical Oncology that is aimed at assessing the outcomes of cancer surgical procedures for specific tumour sites, such as breast, oesophageal, pancreas and rectal cancers and liver metastasis (12). It involves the collection of all the cancer procedures with a detailed list of key clinical variables of all the patients with a specific tumour site, using data from population-based cancer registries when possible, although other comprehensive databases have been used (e.g. discharge information from administrative data sources for pancreatic cancer) (13). This initiative from a scientific society could provide essential clinical and epidemiological data variables combined to compare the performance of different health care systems, either at national or regional level; this will allow a rational discussion about the quality of care provided. The diversity of countries involved so far makes feasible this comparison and, in combination with the professional involvement, makes a remarkable and relevant initiative at EU level.

One of the major challenges is the increasing budget devoted to cancer care because of the cost of all innovative therapies (including but not exclusively drugs) introduced or under evaluation. The relevance of assessing the magnitude of the benefit of the new drugs approved in a rational way is an activity undertaken by the European Society for Medical Oncology. Its Magnitude of Clinical Benefit Scale was developed to grade the effects of new drugs for each tumour and indication, using data from clinical trials or meta-analysis of trials, with different criteria for palliative and curative indications (14). This scale could provide a meaningful ranking of the magnitude of the clinical benefit that could be expected from a new therapy, which is a key variable in order to assess the value of the drug and opens the possibility for more rational policy. The European Society for Medical Oncology is also convening a group to assess access to expensive, innovative cancer medicines in order to explore different policy options and suggest actions either at international or national levels. These activities could be seen as parallel to efforts of the American Society of Clinical Oncology, such as Choosing Wisely (15), or its statement of the value of cancer care (16), all of which aimed at evaluating the options to support a sustainable cancer system and one that allows innovation to be accessible to all patients that may require it.

With a different perspective, the European Society for Radiotherapy and Oncology has set up a group to assess the status of equipment, workforce and guidelines for planning radiotherapy in all European countries, as well as to assess the need for radiotherapy treatment using an evidence-based model of the indication for therapy (17–20). A further development of the Health Economics

in Radiation Oncology Group will be building a model for assessing the cost of radiotherapy and the analysis of reimbursement by country. The perspective used is a combination of the collection of data at the national level with common methodology, allowing for cross-national comparisons with adjustment for the population-based cancer incidence, which provides a set of data useful for national cancer plans and for assessing the gap between optimal and actual use of radiotherapy (19).

The last example is the ongoing programme launched by the European Cancer Organisation, the umbrella organization of cancer societies in Europe, on the essential requirements for quality cancer care, which will be focused by tumour site, with the first being colorectal and bone and soft sarcomas. This initiative will combine the evidence base with expert input to evaluate the resources required to offer quality care, including its organizational aspects. Another interesting current activity is the programme launched by the European Cancer Organisation and the European Oncology Nursing Society on the evaluation of the role of nursing on cancer care and the analysis of different countries as comparative case studies to assess the evolution of the nursing role in the EU.

## The need for system-level guidance on comprehensive cancer control

### The role of the CanCon Guide

Given all of the ongoing scientific activity and clinical advances related to cancer, it is important to situate CanCon's effort to create the European Guide for Quality Improvement in Comprehensive Cancer Control among other work. Cancer control is not a topic that lacks input from different sources: it is inundated with guidance and recommendations from numerous perspectives and vantage points, including patients, families, clinicians, health care managers, health system leaders, researchers/scientists and policy-makers. While there is an abundance of clinical guidance directed to cancer care professionals – the clinicians and care providers who work with cancer patients on a daily basis – the key guidance gap is on how policy-makers and leaders of cancer control agencies can use available levers to support and facilitate the achievement of optimal performance within prevailing political, economic, social and technological constraints of the broader health care system and jurisdiction. There is a need for health system guidance that addresses key elements of comprehensive cancer control, including organization/governance arrangements, financing arrangements, delivery arrangements (including human resources, technology resource planning, allocation/distribution), all within the span of control of policy-makers and cancer control organization/agency leaders (21–23).

Given this target audience, other forms of guidance do exist. For example, cancer control plans are a widely used form of guidance for cancer control systems. Most high-income countries have a cancer control plan or strategy document that outlines high-level objectives for improving various elements of cancer system performance across the continuum of care (24,25); this is ideally linked to regular surveillance and monitoring of system performance. However, cancer control plans do not typically aim to provide guidance on implementation nor is there sufficient other system-level guidance for cancer control. The CanCon Guide aims to help policy-makers and cancer organization/agency leaders understand the research, contextual and experiential evidence base from which to guide implementation of improvements to key elements of cancer control.

## Four areas of focus

The CanCon Guide targets four distinct but related areas of focus, discussed in detail in Part II: cancer screening (Chapter 4), CCCNs (Chapter 5), community-level integrated cancer care (Chapter 6) and cancer survivorship and rehabilitation (Chapter 7). The Guide is structured to link these four areas of focus both practically and aligned with an overarching trajectory of cancer control from prevention to palliation. This begins with a focus on cancer screening, which clearly sits in the prevention sphere and is typically built upon organized and structured programmatic approaches that touch on many elements of health care systems. The second seeks to establish CCCNs through improved coordination and integration of cancer control treatment centres within health care systems. This sets the stage for focus on community-level cancer care, acknowledging the extension of care and services for cancer control from oncology-specific settings to more general primary care settings. The final and closely related area of focus is cancer survivorship and rehabilitation, representing an area of intense change and development that acknowledges cancer control successes and emphasizes the implications of the increasingly chronic nature of the disease.

Overall, these four areas of focus, while not an exclusive set, do represent big topics and tough challenges that are not consistently prioritized and that reflect a mix of solutions with varying resource needs. The CanCon Guide offers the opportunity to explore and compare different cancer control system perspectives to look for commonalities and differences. The intent of the Guide is to contextualize the challenges and distil key lessons learned for policy-makers and cancer control organization/agency leaders across Europe, flagging opportunities for action and highlighting potential successes that can be achieved.

## Summary of Guide recommendations

Part II of this book provides an in-depth description of the approach and methods taken for each of the four areas examined, a review of the available evidence and the rationale supporting the recommendations made. For brevity, only the summary recommendations for each of the four areas of focus are provided in Box 2.1.

### **Box 2.1** Cancer screening

Policy recommendations on governance, organization and evaluation of cancer screening

#### **Governance of cancer screening**

1. Successful evidence-based cancer screening needs a competent, multidisciplinary and transparent governance structure with political, financial and stakeholder support.
2. The legal code should provide a specific framework for population-based cancer screening, enabling as a minimum the following basic functions: personal invitation, mandatory notification and central registration of complete screening and outcome data and individual linkage to cancer and cause of death registries for appropriate quality assurance including audits.
3. Successful implementation of effective cancer screening programmes requires significant resources for quality assurance, that is 10–20% of the estimated total expenditure of a full-scale programme.

### **Organizational requirements**

4. Implementation of population-based screening should be a carefully managed multistep process through the phases of coordinated planning, piloting, rollout and continuous improvement.
5. The mandate and resources for screening coordination and training, and for the electronic information systems necessary for quality assurance and incremental improvement, must be secured before starting the population-based screening service.

### **Integrated evaluation**

6. To secure the benefits of screening, routine linkage between the registries containing relevant data for defining the population, performance and outcome is essential and can be considered an ethical requirement of screening.
7. Whenever relevant, evaluation and regular monitoring of cancer screening should also detect social inequalities and trigger research and interventions on improved equity in health. Research collaboration has an added value to develop interventions and solutions in the local settings where social barriers and social inequalities in cancer have prevailed.
8. Benefits and harms of screening need to be clearly communicated to the public; a scientific consensus on the appropriate estimation method and estimate would be of great value as the appropriate balance may be judged differently by individuals.
9. The cost-effectiveness of a programme or a specific modification of it should be evaluated prior to deciding on the full implementation. Member States should define a threshold value for decisions on cancer screening, considering affordability and available resources.
10. Indicators for quality and effectiveness based on most recent evidence-based reviews should be monitored and acted upon regularly by updating the screening programme.

### **Potential new cancer screening programmes**

11. Quantitative estimates of the benefits, harms and cost-effectiveness of possible new cancer screening programmes are needed to decide on implementation. It is essential that the EU Member States finance randomized trials designed to produce information necessary for policy-making and investments are needed so that results become available in as early phase as possible.
12. Active European research collaboration and pooling of results from randomized controlled trials and related health-economical assessments are necessary in order to obtain evidence relevant for the different settings, with potential variations in the burden of disease, health priorities, effectiveness, resources and affordability found among the European countries.

## **Comprehensive cancer control networks**

### ***Confronting the problem of inequality in cancer care***

1. We recommend in order to reduce travel distance to quality cancer care, one of the many cancer care inequalities, access points and patient pathways should be clearly defined, access points are as close as possible to where patients reside and that uniformly optimal care be provided as close to home as possible.

### ***Structure, infrastructure and governance of a CCCN***

2. We recommend that a CCCN be a multicentric complex, combining units dealing with the management of all aspects of cancer care. These units will be in different locations and under a single governance structure. They will undertake to collaborate consistently in a structured way, in order to pursue their common goal with greater effectiveness and efficiency.

### ***Care of cancer patients in a CCCN***

3. We recommend that a CCCN adopts a multidisciplinary personalized approach based on tumour management groups integrating specialized hospital care with care in the community, palliative care, psychosocial support, rehabilitation and survivorship care plan.

4. Quality of care within the CCCN should be measured with quality indicators. A process for continuous quality improvement should be put in place and implemented.

5. For each type of rare cancer, we recommend identifying within a CCCN which unit if any can provide the necessary expertise. If for a certain cancer no suitable unit can be identified, the patient should be referred to an appropriate unit outside the CCCN.

### ***Cancer research in a CCCN***

6. We recommend that a CCCN takes full advantage of the proximity of patients, researchers and care providers to pursue high-value basic, translational, clinical outcome and population research programmes to fully support the delivery of optimal patient care within the CCCN.

### ***Decision-making process for creating a CCCN***

7. Given the benefits that a CCCN can provide with respect to equity of access as well as quality of cancer care, it is recommended that the creation of one or more CCCNs is always considered in decision-making. When in a certain area a CCC already exists, a CCCN can be built based on it. Performance indicators and evaluation models should be defined from the outset of the network.

## **Community-level cancer care**

EU policy recommendations for quality improvement in cancer after-care at the community level.

**1. Manage cancer as a continuous process where patients pass (transit) different phases and stages.** This can be achieved through the creation and updating of a cancer patient pathway going from screening outcomes through diagnostics and treatment to long-term monitoring in remission, life-prolonging treatments and palliative and end-of-life care.

This should:

- (a) reflect the current level of knowledge in cancer treatment but also the specifics of the country's health care system and its organization;
- (b) secure the necessary resources – human, financial, equipment and medicines – at all stages of the pathway;
- (c) develop the segment of the pathway for the cancer patients' after-care in close collaboration between specialized oncological care and primary care providers; and
- (d) organize an information exchange platform that enables all providers involved in cancer patient care to share the data and files relevant to the patient.

**2. An obvious need for coordination and organization through the creation of multidisciplinary teams at all levels and in the development of a survivorship care plan.**

**3. Dynamic coordination and flow of information between the oncological specialized care and community care, necessary for the following reasons:**

- (a) the proper organization of seamless care when patients move between levels;
- (b) mutual exchange of information concerning both the patient's condition and disease before cancer as well as specifics of the cancer treatment, including side-effects, disabilities and long-term effects;
- (c) the management of a proper uniform patient file bearing all the relevant information; and
- (d) the assessment of the long-term patient needs for community care related to monitoring of cancer in remission.

**4. Organization of education and training for primary care providers.** This is needed in order to strengthen providers' capacity to cope with the increasing population of cancer patients in after-care.

**5. Development of guidelines and guidance, at least for each of the most frequent cancers, on what to include and on what not to include in long-term monitoring of patients (system specific, differences in access to some tests and diagnostics), to include the following segments:**

- (a) recurrence detection, indicating the best frequency to perform diagnostic tests to detect cancer recurrence; the description of the signs and risk of recurrence in a given category of patients; and, finally, recurrence detection defined and elaborated for patient after-care in terms of the responsibilities of GPs (in case they are willing to perform this role);
- (b) long-term effects of cancer with more information on the potential complications of individual types and locations of cancer and how these should be prevented and treated; more knowledge and recommendations on psychological support for cancer survivors are warranted; and
- (c) recurrence prevention, with more research into the value of recurrence prevention and specific recommendations for cancer survivors.

**6. Coordination between the health and other sectors for many patients, not only for those that become disabled or are terminally ill.** Treatment itself, long absences from work or treatment away from family may raise all sorts of problems (e.g. additional expenses or less of productivity).

## **Cancer survivorship and rehabilitation**

Policy recommendations for quality improvement in cancer survivorship and rehabilitation for EU Member States.

### ***Medical follow-up: focus on late effects and tertiary prevention***

**1. An early and personalised follow-up programme should be systematically planned and delivered to each survivor:**

(a) adequately assessing the survivors' individual risk of multidimensional late effects of treatment and respective rehabilitation needs (e.g. physical, psychological, social, cognitive, sexual, nutrition); and

(b) creating opportunities for socially disadvantaged people to fully engage in follow-up programmes.

**2. Adequate and updated information on medium and long-term effects of treatments should be available:**

(a) to survivors and their relatives; and

(b) to care providers involved in the follow-up, in particular primary care professionals, for better prevention and care.

**3. Identification and management of late effects of cancer treatment should be integrated in the professional training and continuous medical education of clinicians (including GPs).**

**4. In tertiary prevention, self-management should be emphasized, particularly on lifestyle recommendations and on the risks of long-term effects:**

(a) smoking cessation;

(b) weight control and healthy diet including limited alcohol consumption;

(c) sufficient sustained physical activity;

(d) avoidance of excessive exposure to ultraviolet radiation; and

(e) stress management.

**5. Physical activity should be integrated early in the care pathway for all cancer survivors.**

It should be an important component to consider at every phase of survivorship care for all survivors in order to maintain healthy lifestyle.

**6. Evaluation of physical and psychosocial rehabilitation needs should first be screened as follow:**

(a) baseline screening should be performed prior to the start of any cancer-specific treatment;

(b) both physical and psychosocial screening should be carried out simultaneously by using simple algorithms; for physical screening, at least the following items should be screened: cardiac function, muscle strength and flexibility; for psychosocial screening, see item 8 below; and

(c) after the first screening, regular updates should be performed on individual basis.

***Needs for a person-centred approach in psychosocial rehabilitation, supportive and palliative care***

**7. Periodic screening of psychological distress and psychosocial needs should be conducted:**

(a) during the entire cancer pathway by the health care professionals (e.g. oncologists, physicians and nurses) and integrated in routine cancer care; and

(b) screening should be followed by adequate provision of psychosocial care.

**8. For the diagnosis of psychological conditions a specific assessment should be carried out by a psychological care professional:**

(a) using validated and simple tools and according to clinical practice guidelines for the assessment and management of psychological distress and morbidity; and

(b) anticipating the specific needs of populations at high risk, including young populations (e.g. children, adolescents, young adults) and relatives.

**9. A step-wise or tiered model of psychological care is recommended depending on the level of distress, psychological condition and morbidity of each patient, with interventions ranging from:**

(a) information and psycho-education by primary oncology team to peer support;

(b) e-health platforms for psychosocial support and self-management programmes;

(c) Psychological interventions by professionals trained in psycho-oncology (e.g. psychologists, social workers, psychiatrists);

(d) complementary spiritual support by chaplains and others; and

(e) psychotropic treatments by trained physicians (e.g. psychiatrists, oncologists).

**10. Psychosocial interventions in individual or group format should be delivered by appropriately trained professionals with specific expertise in psychosocial oncology.**

**11. Increased investment in training in psycho-oncology and communication skills for primary oncology staff is highly recommended.**

**12. Existing clinical practice guidelines for psychosocial support of patients with cancer could be highly valuable and recommended for the provision of evidence based psychosocial care.**

**13. Social and return-to-work issues should be integrated early into the cancer care pathway.** Adaptation of working conditions for any patient returning to his/her previous work should be assessed at early stages.

**14. Public policies should be developed and implemented to support cancer patients from diagnosis to return to work including:**

- (a) financial aspects such as access to loan, mortgages, life insurances;
- (b) implementation of a pan-European strategy to tackle the differences between workers with cancer in different countries and to prevent discrimination; and
- (c) generation of more evidence to better understand the living conditions of cancer survivors who return to work.

**15. A person-centred approach should be implemented:**

- (a) to access a multidimensional physical and psychosocial rehabilitation plan focusing on the skills of cancer survivors;
- (b) to safeguard cancer survivors' working lives; their employability, competencies and capacity to work, as well as their motivation to work; offer new skills to self-employed workers to help them to achieve balance between health needs and work;
- (c) to involve peers, patient organizations and trade unions to help patients and survivors; and
- (d) to negotiate a patients' bill of rights, including the right to work with special conditions (e.g. reduced hours of work or adapted working conditions).

**16. A work-centred approach should be implemented with a better involvement of employers in survivors' return-to-work process:**

- (a) to explore possibilities of changes in job function for cancer survivors and to encourage them to acquire new skills;
- (b) to facilitate the implementation of flexible working hours and options (remote working, part-time work); and
- (c) to offer economic benefits to employers who agree to adapt the workplace to the needs of cancer survivors and to help self-employed workers to adapt their workplace and business to address health needs.

**17. Somatic and psychological symptoms as well as social challenges should be addressed in all phases of the cancer disease trajectory early, systematically and regularly.**

Treatment should be according to the best scientific evidence available.

**18. Formal education in palliative care should be a compulsory component of the professional curriculum for specialists in medical oncology, for GPs and community clinicians:**

- (a) basic training should be mandatory in medical and nursing schools; and
- (b) specialized palliative care skills and services should be accessible to patients with advanced incurable disease and part of multidisciplinary tumour boards.

**19. Best achievable quality of life for the individual patient and the relatives should be part of a survivorship care plan for patients with late side-effects from cancer and antineoplastic treatments.**

***Multidisciplinary approach in survivorship care: coordination of providers and empowerment of survivors***

**20. Psychosocial care, rehabilitation and palliative care should be integrated into the entire cancer pathway including the survivorship and rehabilitation period.** Psychosocial, rehabilitation and palliative care specialists should be members of (or associated with) the medical team in hospitals and in community care.

**21. After the completion of the acute treatment phase, the follow-up period should begin with the elaboration of a survivorship care plan.**

**22. The role of GPs and other primary care professionals should be actively supported to help them to manage all the care plan challenges:**

(a) their role should be clearly defined and tailored to the patient and the care plan needs; and

(b) this role could evolve during the follow-up period.

**23. Communication between primary health care providers and health care specialists needs to be improved:**

(a) electronic patient records systems should be accessible to all health care providers treating the patients; and

(b) communication between patients and health care providers should be improved.

**24. A key health care professional assuming a case management role should be assigned to each patient in accordance with medical and/or psychosocial specific requirements.** This health care professional could play a main role in reducing the vulnerability of the patient, for example with the management of adverse drug effects.

**25. Empowerment of patients and their relatives should be enhanced to increase their participation in self-management, rehabilitation and back to work programmes.** Online programmes would facilitate this process.

**26. Education and self-management programmes should be developed and evaluated:**

(a) better access to these programmes should be available for underserved and deprived populations (low income/low education);

(b) assessment of patients' needs should be systematically part of the development of an education programme; and

(c) evaluation of these programmes should assess the impact on the personal, organizational and health care policy levels, including cost-effectiveness and impact on health care quality.

**27. Training of health care professionals should include communication skills alongside medical education:**

(a) regarding information/communication/knowledge of survivorship and rehabilitation needs; and

(b) management of late effects.

### ***Childhood, adolescent and young adults issues in cancer survivorship care***

28. Transition of care from pediatric oncology to adult medicine, including a survivorship passport for each patient, should be organized to guarantee adequate long-term follow-up and setting up appropriate intervention (26).

29. It is necessary to aim for a more efficient survivorship care planning and coordination to respond to the challenges of the prevalence of chronic conditions, health status deteriorations, treatment and complex prevention. Determining the most effective models of care for childhood cancer survivors is the main step forward.

30. Rehabilitation and supportive care should be specifically offered to children, adolescent and young adults as cancer survivors, in particular adapted physical activity. A routine yearly psychosocial assessment with attention to social, psychological, and behavioral issues, educational and/or vocational progress should be provided to this population.

31. End-of-life care and palliative care for children and adolescents should be improved across Europe.

### ***Perspectives in survivorship and rehabilitation cancer research***

32. An information and data collection system focused on late adverse effects (physical, psychological, cognitive, social, sexual), coupled to the surveillance of patients and involving primary care professionals, should be set up. More patient-reported outcome measures and their routine use are needed.

33. Use of cancer registries to collect data on survivors would produce stronger epidemiological data, including lifestyle, quality-of-life or socioeconomic information:

- (a) to better identify the causes of inequalities in survivorship;
- (b) registries should be expanded to include additional factors that influence the quality of life (e.g. rehabilitation and employment issues);
- (c) patient reported outcomes could also be a way to collect appropriate information.

34. Clinical research should evaluate the feasibility, the efficacy and the cost-effectiveness (including the economical dimension) of non-drug-related interventions such as self-management and e-health programmes.

35. Future research is needed to establish a multidimensional rehabilitation model focused on the quality of life and the coordination of complex care to better address the management of late effects across the whole survivorship trajectory. More research would also be required to maximize the long-term follow-up and care of childhood cancer survivors and to identify the genetic risks associated with late effects and second cancers.

36. More solid methodological randomized controlled trials and cohort studies are needed in order to reduce the intensity of cancer treatments while maintaining their efficacy and thus reducing the probability of late effects, especially in childhood cancer survivors.

## Appraisal of the Guide recommendations

The specific recommendations for each of the four areas of focus highlighted above are detailed in Part II. In the remainder of this chapter, comment on the methodological approach taken is presented, as well as consideration of common themes across the four areas of focus and identification of some key gaps that this Guide has not addressed.

### Comment on methodological approach taken

As the CanCon experience reveals, it is not easy to get a broad collection of stakeholders from many different countries to pursue similarly rigorous methodological approaches that can yield useful insights to guide policy and practice. Yet, at the same time, the act of coming together and discussing important issues in earnest can lead to invaluable insights and shared learning. Evidence for policy cannot rely solely on research evidence, but also requires contextual evidence (e.g. measurable information and characteristics related to geography, sociodemography, system/organizational structure/capacity and economic, cultural and political factors) and experiential evidence (e.g. tacit knowledge and collective professional/practical insight and expertise) (27). The intent of the CanCon approach was not to rely exclusively on rigorously conducted systematic reviews of research literature, but rather to have work package teams that would combine reviews of relevant literature with assessment of experiential and contextual evidence, drawing on team members' knowledge of contextual factors that influence country-specific situations. Overall, a main intent of the Guide is to draw on the comparative experience of the participating European countries and cancer systems to provide guidance on the four areas of focus.

### Common themes and gaps

There is in-depth consideration of each of the four areas of focus and their respective recommendations in Part II of the Guide. The Guide's 62 recommendations across the four areas of focus required consideration of the perspective of the target audience – policy-makers and cancer organization/agency leaders – and their overarching responsibilities to assess the common themes that have arisen from this work and key gaps that may represent areas to target for future work.

### The system level and the need for improved coordination/collaboration

Although quality improvement is part of the title of the Guide, emphasis on quality improvement is subtle throughout. Quality improvement typically references clinical contexts and efforts but the focus of the Guide is more aligned with broader improvement science and emerging thinking on health system strengthening. The system level received a lot of attention, but the main elements of health systems (e.g. understanding and improving governance and financial arrangements and the structure and organization of service delivery) were not consistently addressed by each area of focus. Despite the lack of consistency, there was considerable attention throughout the Guide on system-strengthening components. The cancer screening recommendations did, in fact, comprehensively cover governance, financial, and service delivery arrangements, while recommendations for integrated cancer control were orientated towards policy-makers and directly addressed governance arrangements and decision-making processes.

The cancer survivorship/rehabilitation and community-level cancer care recommendations focused mostly on service delivery arrangements. Much of this relates to how providers can work together in more coordinated and collaborative ways, including improving how patients transition from provider to provider and care setting to care setting. Throughout the Guide, there are repeated calls for greater multidisciplinary work and interprofessional collaboration among different levels of care and for multicentre work beyond the health care sector. This should be a key overarching focus for policy-makers and cancer organization/agency leaders to accentuate. However, while integrated cancer control is clearly a prominent focus for the Guide, there is more work needed to understand the nature of existing networks of cancer control organizations and the potential requirements for establishing a more comprehensive network for cancer control within varying health system contexts.

Being at the frontline of cancer control means tackling increasing and interconnected challenges and areas of care (e.g. survivorship and quality of life; psycho-oncology and genetic counselling) that require the development of multistakeholder strategies when formulating and implementing new approaches and actions on cancer care. Importantly, the EU through CanCon and EPAAC has become a reference for thinking on those approaches where the impact is expected to be meaningful, tackling the broader patient needs along the continuum of care.

### **The patient perspective**

Three of the Guide's four areas of focus gave considerable attention to the patient perspective, consistent with the patient-centred approaches that have begun to dominate health systems thinking since the early 2000s. Recommendations for cancer survivorship and rehabilitation and for community-level cancer care emphasize the importance of self-management and the patient pathway, while the integrated cancer control recommendations were centred on the need to make access for patients more equitable. Only the cancer screening recommendations did not address patient-specific issues directly. The consideration of the patient perspective is a key theme of the Guide and a prevailing theme of health systems generally, and patient organizations, such as the European Cancer Patient Coalition or the European Cancer League, are key contributors to improving cancer control. Policy-makers and cancer organization/agency leaders can influence the potential of patient-oriented approaches to advance cancer control by establishing and reinforcing patient organizations as a core strategy.

### **Research and information**

Unsurprisingly, another set of common themes in the Guide relates to the need for research and information on cancer control. Research is needed in many areas, from basic and applied research to clinical data systems to system-level performance measurement/reporting to detailed assessment of health system contexts. A previous European effort (EPAAC) targeted research and cancer information needs, particularly related to clinical settings and health outcomes; however, there is a notable need for targeting research and information investments on the system level. Each of the Guide's four areas of focus include recommendations for better coordination and collaboration on research and/or information sharing to support improved cancer control. An underlying emphasis for greater collaboration and coordination on research and information sharing reflects both efficiency and effectiveness needs. The cancer screening recommendations, for example, include the need for collaboration to efficiently produce high-quality evidence from randomized controlled trials (RCTs) that takes account of changing incidence of disease (e.g. the consequences of immunization for human papilloma virus (HPV)). The cancer survivorship and

rehabilitation recommendations encourage improvements to health informant technology and electronic health records, while the community-level cancer care recommendations comment on the importance of information sharing and long-term monitoring. As the push for more integrated approaches to cancer control evolves, the need for shared information sources, both within and across health systems, will only continue to grow.

While the Guide emphasizes research and information-sharing needs, there is limited specific focus on performance measurement and reporting at multiple levels (e.g. clinical, health services and systems, population health). Given the importance of the four areas of focus covered in this Guide, there is a corresponding need to deliberately advocate and direct the development of performance measurement capacity related to these areas. This includes development of common sets of performance indicators, benchmarks and approaches to target setting that address the recommendations put forward in this Guide. Furthermore, performance measurement systems are particularly useful in identifying promising practices that can be shared across systems and jurisdictions.

The Guide is not accompanied by detailed country-specific information on the cancer control and health system context. Country contexts and health system features can influence the nature of a specific cancer control problem. Understanding of the challenges may be specific to the country, given the relative emphasis/focus on the problem and efforts to monitor and evaluate the effects, develop and implement solutions. For example, it has been shown that the coverage and variables collected for population-based cancer registries vary widely across different countries in Europe (28), affecting assessments of the feasibility and impact of cancer plans and interventions. While contextual and experiential insights are implicitly addressed through the multicountry participation for each area of focus, some of this context-specific information that underlies the recommendations may not be apparent to interested system stakeholders. As part of aims to enhance performance measurement capacity, there is an opportunity to contribute to more detailed contextual analyses of the system features relevant to cancer control systems in order to facilitate interpretation of country-specific efforts and their transferability and applicability to other jurisdictions.

### **Resource needs and the economic rationale**

The Guide provides 62 recommendations but demands for new resources are mostly muted, largely reflecting the economic context within which this work has been produced. While there are some specific requests for investment (e.g. training of clinicians in survivorship and rehabilitation), the Guide puts a very limited economic analytic lens to the recommendations. While beyond the scope of the current Guide, understanding of and insight on opportunity costs of the recommendations are critical. Injecting economic evaluations to more clearly distinguish the needs from the wants represents an important opportunity to extend the value of the Guide to give policy-makers and cancer organization/agency leaders the type of information needed to establish sound value propositions for investment decisions.

### **Impact of non-health sectors**

Another theme that was emphasized by two areas of focus in the Guide addressed the need for coordination and collaboration with non-health sectors. Both community-level cancer care and cancer survivorship and rehabilitation recommendations emphasized the role that non-health sectors/stakeholders (e.g. social/employment policy-makers, banking/mortgage agencies, life insurance providers) can have on the well-being of those who survive cancer. Health policy-makers

and system-level leaders are uniquely positioned to facilitate interaction with non-health sector stakeholders. While experience suggests that it is quite a challenge, the Guide's recommendations illustrate the important need to support interactions with non-health sectors and represent an area where health policy-makers can provide crucial additional value to cancer control efforts.

## Cancer control opportunities

As previously noted, cancer control is a complex and challenging topic. This Guide intended to target policy-makers and leaders of cancer agencies/organizations on ways to improve cancer control from a health systems perspective, with four work packages directing focus towards four key topics: cancer screening, integrated cancer control, community-level cancer care and cancer survivorship and rehabilitation. These four key areas of focus for comprehensive cancer control have yielded 62 recommendations that need to be pursued. Appraisal of these recommendations also highlights a number of key gaps that were not directly addressed through this work but represent future opportunities to improve cancer control in Europe.

Ultimately, the Guide needs to inform and direct its target audience – policy-makers and cancer organization/agency leaders – as much as those actively involved in the provision of cancer care day-to-day to take action. However, the 62 recommendations can read both like a comprehensive assessment and a somewhat bewildering starting point for improving cancer control. The key opportunity going forward is to make the 62 recommendations in the Guide actionable at the level of national cancer plans without missing the European-wide perspective. The CanCon perspective shows that it is feasible to learn from country-specific experiences, as is detailed in several of the following chapters of the Guide, and to combine these experiences to generate an opportunity to progressively build European cancer control policy. This approach, combining both national and a broader European perspective, can complement parallel initiatives, such as the European reference networks or the oncopolity perspectives proposed by different scientific societies or patient organizations, such as EURORDIS, Rare Diseases Europe, the European Cancer League or the European Cancer Patient Coalition.

To operationalize the Guide's recommendations for the advancement of comprehensive cancer control, there are a few key questions that should be put pursued. In the prevailing zero-sum investment context, which recommendations are the clear priorities? Who, specifically, should each recommendation be directed to in order for tangible action to be taken? What needs to be done to monitor those efforts and the potential results?

The demands on cancer control are not going away and will only grow more challenging. The recommendations outlined in this Guide represent an important step in preparing our health systems for the evolving challenges. Enthusiastic contributions from our diverse CanCon team have been a crucial part of the valuable CanCon experience; we encourage continued collaborations with patients, clinicians, health care managers, researchers and other stakeholders from across Europe to help to operationalize the shared lessons learned and advance comprehensive cancer control.

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# Part II



# Methods and quality assurance process applied in the development of the Guide

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## Introduction

Joint actions are a particular form of collaborative projects between Member States to gain expertise in domains where the responsibility largely remains at the level of each EU Member State. Consequently, coming to a common output within the context of a joint action requires a particular process coordinating and facilitating the interactions between the different partners, stakeholders and Member States. We have built on the experience gained in EPAAC, the previous Joint Action on Cancer, in which most CanCon partners already participated. As the final output of this Joint Action, CanCon, is a single Guide document, it was recognized that in addition to a general administrative and financial coordination, a dedicated team providing the general structure of the guide and monitoring its development and the structure would be important.

A specific work package led by the Belgian Cancer Centre of the Scientific Institute of Public Health was created that would be aided by the Guide coordination team to oversee the development of the CanCon Guide document. The aims of this work package is to (i) ensure coherence and quality of the guide document, (ii) provide guidance and support for collecting the material used for drafting the policy recommendations within the core sections, and (iii) support the inclusion of two cross-cutting issues within each core topic: inequalities and cancer information systems.

## Guide Coordination Committee: quality assurance process applied in the development of the Guide

To maintain the quality assurance of the project, a so-called Guide Coordination Committee was installed at the start of the project. The Guide Coordination Committee represents the work package leaders, European Commission representatives, the work package 4-associated partners and two external experts (Table 3.1). The European Observatory on Health Systems and Policies assisted the Guide Coordination Committee in the development and compilation of the Guide.

**Table 3.1** Composition of the Coordination Committee for the Guide

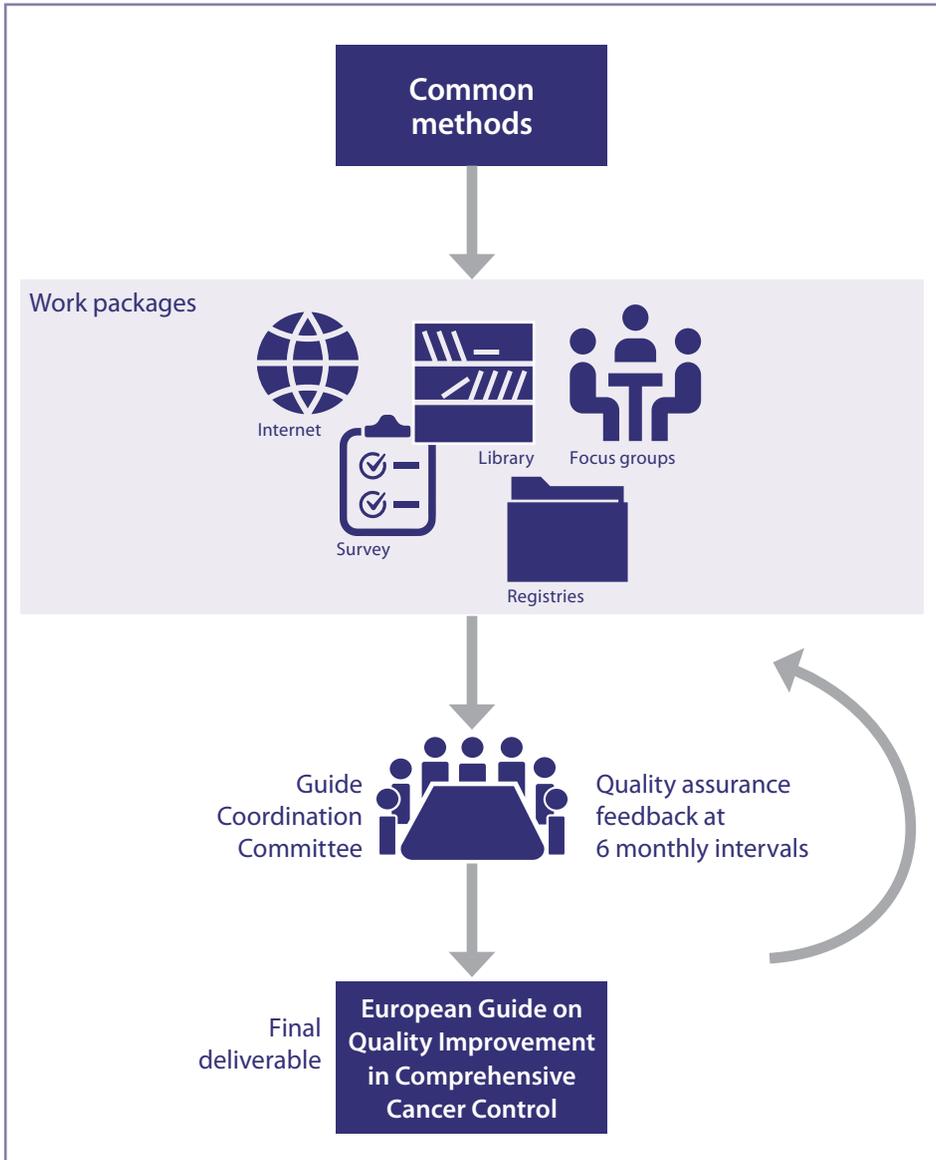
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The main tasks of the Guide Coordination Committee are to

- endorse the quality assurance criteria to be applied in the development of the core chapters of the guide;
- critically assess the methodological approach in the core work packages;
- propose improvement/changes; and
- approve the final content of the core chapters.

The quality assurance process for the joint action is illustrated in Fig. 3.1. At the start, a common principle of methodology was agreed relating to the collection and use of material for drafting the policy recommendations. For this, literature reviews, surveys, expert inputs and a common evidence appraisal approach alongside incorporating contextual features of the EU health systems are considered of great important.

**Fig. 3.1** The quality assurance process in development of the Guide



Through biannual meetings, the Guide Coordination Committee follows the progress of the activities and provides input and suggestions for improvement. After each round of quality assessment, a periodic quality assurance report summarizing the main achievements, potential difficulties and transverse or recurrent issues is prepared and shared with all work package teams. To support the writing teams and ensure coherence and quality, the Coordination Committee provided a glossary of terms as well as a list of existing and validated tools for appraising and judging quality of the evidence collected. A workshop dedicated to the Guide's authors has been organized to present and discuss features of using the collected material to draft policy recommendations. Experts in guidelines and policy recommendation development were invited to share practical experience and guidance tailored to the topics of the four core chapters of the Guide.

## Overview of the methodology applied within the core chapters

Considering the diverse topics covered in the guide, each chapter applied a different combination of approaches to develop recommendations for the policy-makers. Overall, literature reviews, surveys, semi-structured interviews, expert opinions and discussions, evidence grading/appraisal exercises and pilot field studies are the most commonly applied methods (Table 3.2)

**Table 3.2** Schematic view of the approaches applied in the core chapters

<b>CanCon Guide methods</b>	<b>Literature review</b>	<b>Survey</b>	<b>Semi-structured interviews</b>	<b>Expert opinion</b>	<b>Grading or appraisal</b>	<b>Field or pilot study</b>
Screening	X	X		X	X	
Integrated Cancer Control	X	X		X	X	X
Community-level Cancer Care	X	X	X	X		X
Survivorship and Rehabilitation	X	X	X	X	X	

Details on the applied methodologies can be found in each of the core chapters. Below only a brief listing of the different approaches in the respective chapters is presented.

### Work package: Cancer screening

Evidence on efficacy and effectiveness of cancer screening was drawn from recent systematic reviews and European quality assurance guidelines, supplemented and updated also with conventional literature searches using PubMed. Specific literature searches were used for potential new screening programmes for prostate, lung, gastric and ovarian cancer. Rating of evidence was performed and current evidence was discussed at consensus meetings with international experts.

Status reports on the implementation of cancer screening were available from a number of surveys. Supplementary data on current implementation status of cancer screening programmes were obtained through the partners and experts.

Recommendations for the Guide chapter were drafted by the authors of the chapter and delivered for comments and review within the Working Group and the Guide Coordination Committee.

## Work package: Integrated cancer control

Surveys were performed to collect information on CCCNs as a possible model of cancer care organization across Europe, collecting information from representatives of EU health authorities, cancer societies, directors of comprehensive cancer centres, cancer registry directors and from RARECAREnet. Herein, semi-structured interviews with international experts were performed.

Various literature searches were performed using peer-reviewed journals, grey literature and web sites of cancer networks, governments and relevant online databases.

## Work package: Community-level cancer care

A questionnaire-based survey of experts and country informants in 32 countries was performed and international guidelines assessed. Databases and web sites were used in literature and evidence searching.

The findings of five European countries (Bulgaria, Denmark, the Netherlands, Norway and Slovenia) were included given the specific interest in participating shown by their respective ministries of health. The findings are, therefore, a result of self-inclusion and not of a systematic and structured involvement of specific countries. Also, the methodologies used in the different countries in order to substantiate some specificities of their after-care process, relationship between levels of care, and between the central and regional relationships vary greatly. Consequently, there was no overall harmonization of methodologies. In Bulgaria, the National Centre for Public Health Analyses carried out a set of structured interviews on perceptions of after-care services, in particular from the point view of the type of provider. In Denmark, a reform of after-care is in progress including plans on follow-up care for each main type of cancer. For the Netherlands, the Netherlands Institute for Health Services Research (NIVEL), carried out a series of health services research studies and measured the impact on after-care on the volume of care in a general practitioner (GP) practice. The Norwegian case described a health services intervention study where the activities of an ongoing transformation (the transfer of certain specialist services including palliative care to the community level) are outlined. The Slovene study combined a quantitative cross-sectional survey of a stratified random sample of 250 GPs practising in Slovenia, with semi-structured interviews conducted on a purposive sample of six physicians from Upper Carniola region. Good practice recommendations on after-care in GP practices were developed and tested during the study.

## Work package: Survivorship and rehabilitation

Based on preliminary work on existing guidelines or plans for long-term follow-up care for cancer patients, four countries were recognized as pioneers: the United States, Canada and Australia, which follow the work achieved by the Institute of Medicine (1), and the United Kingdom (2). Based on these, five key areas were identified as to be investigated in the field of long-term follow-up care for cancer patients, with specific attention to four cross-cutting issues. The five key areas were

- medical follow-up, including management of late effects and tertiary prevention
- psychological support
- social rehabilitation including employment issues

- empowerment of cancer survivors
- multidisciplinary approach and coordination of care providers.

In addition, four cross-cutting issues were covered

- care for survivors of childhood cancer
- inequalities in survivorship
- cancer information and data registration
- research.

In order to collect evidence about these nine issues and to translate it into policy recommendations for EU Member States, a three-fold methodology has been used: literature reviews, a critical appraisal exercise including a deliberative process involving invited EU experts to discuss the results and their applicability in EU Member States and a survey on current status in EU Member States regarding cancer follow-up care.

## Two cross-cutting issues: equity and cancer information

In the exploratory and preparatory phase of CanCon, partners recognized the importance of two themes, assumed as transversal across the Guide: equity and cancer information.

Equity in cancer was considered in CanCon a key issue to be included as a transversal topic in the Guide. Several steps have been developed in order to ensure the inclusion of the equity perspective in the Guide construction process. This task has been developed in the context of WP4, and was led by the Fundación para el Fomento de la Investigación Sanitaria y Biomédica (FISABIO) de la Comunitat Valenciana.

In order to provide tools that help including the equity perspective in the Guide development, some specific recommendations were provided in the Methodological Paper elaborated by WP4 paper, among other issues, theoretical models such as the social determinants of health model (4), and a glossary of equity terms was presented. The cancer inequalities involve social inequalities in the prevention, incidence, prevalence, detection and treatment, survival, mortality, and burden of cancer and other cancer-related health conditions and behaviors (5). The objective was to harmonize the concepts and terms used in the Guide. For example, it was recommended to use the concept “health inequalities” instead of “health inequities”, because is a much more readily understandable term by the general public and the term “health inequities” does not find a direct translation in all languages. In consideration of these points, this document uses the term health-cancer inequalities with the sense of avoidable and unfair differences in health and cancer (European Commission, 2009). Some examples on social inequalities in the cancer continuum were included in the Methodological Paper in order to provide each WP leader arguments to justify the need of addressing this issue in the Guide (e.g. people living in high deprivation area participate in a lesser extent in colorectal cancer screening than people in low deprivation area (8). In order to consider social determinants of health in the formulation of the issues they addressed, a PROGRESS-Plus tool (meaning place of residence, race, occupation, gender, religion, socioeconomic status, social capital, and others like age, disability, sexual orientation, discrimination, etc.) (7) was provided, as well as key words and MeSH Terms (eg: Socioeconomic Factors [MeSH]...) to use when a literature review was planned.

The tools for mainstreaming equity included in the Methodological Paper were used as quality standards in the revision process of the chapters. A workshop to discuss how to take equity into consideration for evidence-informed health policy-making was made, discussing concrete examples on each chapter.

At midterm, a questionnaire was sent to WP leaders in order to receive feedback on difficulties and opportunities to include equity in the process of chapter development (eg: Have you and/or your partners any difficulties/opportunities to include inequalities as a transversal issue to be described and discussed in the chapter, as CanCon required? Were the equity suggestions we made to your chapter useful for your work? Has been easy to incorporate them in your chapter development?).

Specific equity questions, based on the Equity Checklist developed by the Campbell and Cochrane Equity Methods Group (6) were formulated to assure that the final recommendations of the Guide were equity-oriented (e.g. which groups or settings are likely to be disadvantaged in relation to the policy recommendation?).

A second transversal issue relates to cancer information i.e. the need for presenting data able to document the effectiveness of cancer control activities and assess the applicability of results in most EU health systems.

Administrative and clinical cancer data derived from healthcare facilities, including pathology reports and pharmaceutical data, are essential for the organization of research, clinical practice and can also impact the quality of life of cancer patients physically, socially and professionally.

Cancer information is an essential tool to uncover problems and to quantify their extent in terms of public health. Over 150 European Cancer registries (CRs) in the EU intercept the main data flows generated by these sources to provide cancer basic indicators as incidence, mortality, survival and prevalence, which constitute a key tool for estimating the burden of cancer in populations.

Through linkage with additional population data (e.g. census files, costs/reimbursements for treatments, costs, household surveys, hospital and laboratory files, organized screening registries), further health indicators can be provided by CRs on quality of life, rehabilitation; health assessment technology studies profit from good quality CRs data. Presently CRs data are available via the ECO[ref], and in the next years we can foresee the existence of a European Cancer Information system based at the EC-Joint Research Centre, hosting the "European National Cancer Registries" secretariat since 2012.

From the European Health Information Survey (EHIS), the Organisation for Economic Cooperation and Development (OECD) and EUROSTAT aggregated data on risk factors, early diagnosis, healthcare resources and socioeconomic variables can be derived. Assessment and outcome tools validated in several countries include a connection between population-based data and clinical data, e.g. EPAAC recommendations on multidisciplinary teams, the activity promoted by OEI with the EUROCANPLATFORM PROJECT and the CCC accreditation scheme.

Throughout the action, the consideration of relevant data in the methods was ensured through the promotion of databases including records of clinical decisions, outcomes, indicators, as well as of clinically-based evidences, best practices, cost-effectiveness issues, use of resources and features of different healthcare systems influencing implementation.

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# Cancer screening: policy recommendations on governance, organization and evaluation of cancer screening

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## Main messages

- 1 **National structures for governance of screening** are here identified as important requirements for evidence-based decision-making and for establishing adequate legal, financial and organizational frameworks for effective cancer screening programmes with integrated quality assurance. We recommend transparent, structured and publicly documented decision-making, informed political commitment and broad stakeholder involvement in order to build strong professional support for the aims and means of the screening programme. Governance structures recommended here are currently lacking in many European settings, which may contribute substantially to inequalities in cancer prevention outcomes observed both between and within countries.
- 2 **Organization** for the practical implementation and the continual gradual improvement of population-based cancer screening programmes further requires careful coordination of this multistep process with feedback and corrective modification at each step, plus revolution of the quality circle. Information systems that permit registration and monitoring of process and outcome are crucial for maintaining current levels of quality, and for guiding further improvement.
- 3 **Evaluations** of the benefit-harm balance and cost-effectiveness of screening are required periodically for existing programmes and prospectively for new screening programmes. The population targeted by screening have an ethically mandated right to clear information on benefits and harms for an informed choice about participation. Indicators for equity in participation and health outcomes need to be included in the routine quality assurance capabilities of population-based screening programmes.
- 4 **New screening programmes** require step-wise decision-making which includes the establishment of evidence of effectiveness, benefits that outweigh the harms and cost-effectiveness. Once evidence exists to support these criteria, implementation research in each country is needed to assess the feasibility of fulfilling the national requirements in practice. In light of currently available evidence, some prostate cancer screening policies may be cost-effective but questions remain on the optimal benefit-harm balance. Forthcoming results of European trials are expected to inform policy-making on lung cancer screening in Europe. New trials need to be financed to investigate optimal strategies for gastric cancer screening.

## Introduction

Screening refers to the use of relatively simple tests across an apparently healthy population in order to identify individuals who have risk factors or an unrecognized disease or defect. Box 4.1 outlines the terms used within this chapter when discussing aspects that impinge on screening. A screening test is not intended to be diagnostic, and persons with a positive or suspicious finding must be referred for a confirming diagnosis and necessary treatment (1). It is essential that screening identifies those who are more likely to be helped than harmed by further tests or treatment to reduce the risk of a disease or its complications (2). The WHO criteria for screening (1) date from 1968 and have since been refined to highlight the importance of evidence of an acceptable balance between benefit and harm, integrated monitoring and evaluation, equity, and informed choices based on available evidence (Box 4.2) (3). Based on the criteria by WHO and others (1,3,4), three conditions determine the relevance of a screening programme: there has to be evidence for the effectiveness of screening, that the benefits of screening outweigh the harms and that screening is cost-effective (4). These refined criteria are relevant for decision-making concerning screening programmes in the 21st century and form a backdrop for discussion of the collection of evidence before implementation and in routine monitoring and the decision-making processes concerning screening programmes in this chapter.

### **Box 4.1** Terms used in Chapter 4

#### **Audit**

Audit is the systematic examination of current practice against guidelines or a defined desired standard. Cancer screening audits examine the screening history of cancer patients and controls in order to identify and quantify failures of the screening process and the potential for improvement.

#### **Governance**

Governance in the health sector refers to a wide range of steering and rule-making functions carried out by governments and other decision-makers to achieve and develop the national health policy objectives.

#### **Opportunistic testing**

Opportunistic testing is initiated by individual members of the public or their health advisors. It may or may not be based on national guidelines on intervals, target population and screening tests.

#### **Population-based screening**

Population-based screening is conducted according to nationally implemented guidelines defining who should be invited, how frequently they should be screened and how any abnormalities detected should be followed up and treated. The screening programme identifies each individual to be personally invited from a population register. Adherence to national guidelines is monitored in a screening register. Population-based screening programmes generally require a high degree of organization in order to assure that the invitational activities are performed reliably and effectively and are adequately coordinated with the subsequent steps in the screening process.

**Risk-stratified screening**

In risk-stratified screening, the specific screening policy regarding screening ages, intervals, tests and follow-up algorithms is based on the risk profile of a group of individuals in the population. This may include no screening for those at lowest risk and an unfavourable expected benefit-harm ratio. Risk-stratified screening should not be confused with clinically initiated risk profiling, for example genetic testing of patients with breast cancer and their relatives for follow-up of BRCA positive status. Risk-stratified approaches have a theoretical potential to improve overall cost-effectiveness and benefit-harm ratios of population-based screening programmes.

**Stewardship**

Stewardship in health implies that the ministries in charge of health assume the ultimate responsibility for the management of the national resources to the health benefit of their entire population, by directing the establishment of as good and fair health system as possible and by promoting health aspects in all policies.

**Quality assurance**

Quality assurance encompasses activities intended to assure and improve quality at all levels of the screening process in order to maximize benefits and cost-effectiveness while minimizing harms. The concept includes the assessment or evaluation of quality, identification of problems or shortcomings in the delivery of care, the design of activities to overcome these deficiencies and follow-up monitoring to ensure effectiveness of corrective steps.

**Box 4.2 Synthesis of emerging screening criteria proposed since 1968**

- The screening programme should respond to a recognized need
- The objectives of screening should be defined at the outset
- There should be a defined target population
- There should be scientific evidence of screening programme effectiveness
- The programme should integrate education, testing, clinical services and programme management
- There should be quality assurance, with mechanisms to minimize the potential risks of screening
- The programme should ensure informed choice, confidentiality and respect for autonomy
- The programme should promote equity and access to screening for the entire target population
- Programme evaluation should be planned from the outset
- The overall benefits of screening should outweigh the harm

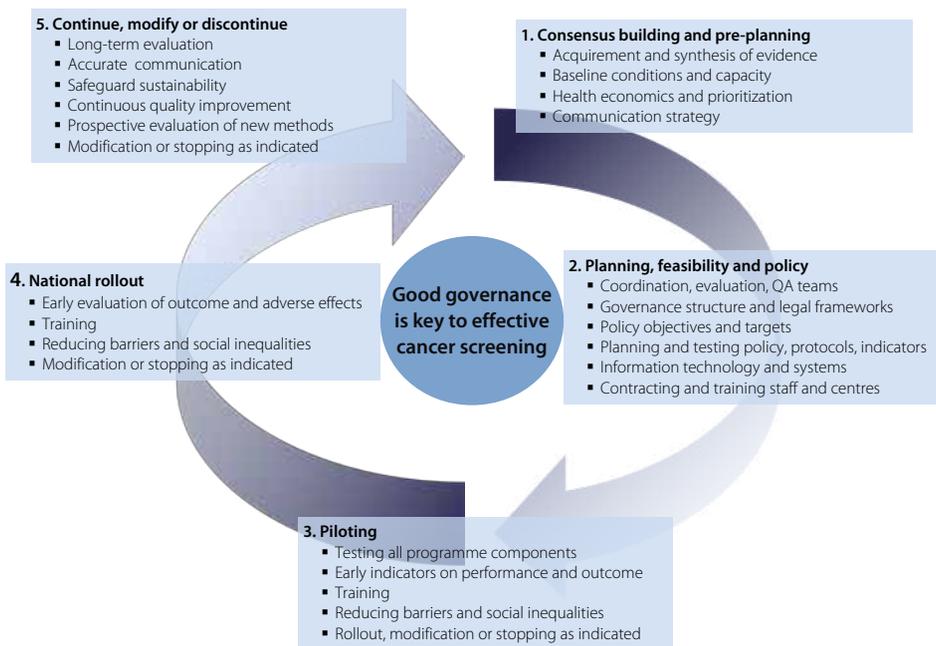
Source: Andermann et al. 2008 (3).

In agreement with the WHO criteria, the Council of the European Union has recommended cancer screening with a systematic population-based approach and quality assurance at all appropriate levels (5). Screening programmes are recommended for breast, cervical and colorectal cancers in

agreement with evidence-based guidelines. According to the final report on the implementation of the Council recommendation on cancer screening, most EU countries are planning, piloting or implementing population-based screening programmes for breast, cervical and colorectal cancers (6). However, there are deficiencies in utilization of some programmes (e.g. because of very low attendance rate), indicating ineffectiveness and likely social inequalities, and in the monitoring and evaluation capabilities required for comprehensive quality assurance.

The quality-assured implementation of cancer screening for the above three cancers involves careful planning and piloting, and scaling up from pilot to sustainable full-scale national roll-out based on social and service provider acceptance (7,8). Fig. 4.1 illustrates various steps and phases of the process. Formulation of a screening policy proposal requires evidence on the effects of screening, disease burden, quality-assured testing and treatment and primary prevention possibilities. Adequate performance must be verified from the beginning, allowing the detection and correction of potential undesirable trends. When problems are identified, the activity needs improvement, reorganization or even discontinuation (Fig. 4.1) (2,7,9). Modifications of existing programmes are also needed to reflect developments in screening, diagnostic and treatment methods, or because of developments in complementary primary prevention (e.g. HPV vaccination). Systematic quality assurance needs continuous well-integrated interplay between policy-making, evaluation and implementation.

**Fig. 4.1** Examples of tasks of organization, evaluation and governance in different phases of implementation and quality improvement of a cancer screening programme



The purpose of the chapter is to produce further advice and guidance for the development and implementation of cancer screening in the EU Member States in accordance with the EU Council recommendation and the current European quality assurance guidelines. Given their scale, population-based programmes need solid governance structures. Appropriate legal frameworks are required to run and monitor organized programmes and evaluate their outcomes; in addition, human and financial resources are needed for assuring the appropriate organization and quality control (5). The chapter presents 12 recommendations covering the spectrum of themes relevant for initiating and running population-based cancer screening programmes: governance of cancer screening, organizational requirements, the need for integrated evaluation and the approach and considerations for potential new cancer screening programmes. Solid screening governance is necessary throughout the process illustrated in Fig. 4.1. The organizational requirements deal with key issues, particularly for building capacity and capabilities in phases 2 through 4 outlined in Fig. 4.1. Integrated evaluation is necessary to inform actions at each step of the cycle. Before exploring these themes, the methodology and evidence base are described.

## Methods

Evidence on efficacy and effectiveness of cancer screening was drawn from recent systematic reviews, and European quality assurance guidelines with ratings of evidence were utilized. The information was supplemented and updated also with conventional literature searches using PubMed. The most relevant guidelines and systematic reviews used were: European guidelines for quality assurance on breast (10,11), cervix (8,12) and colorectal (13) cancer screening; WHO position paper on mammography screening (14); IARC Handbook on Breast Cancer Screening (15); Cochrane review on colorectal cancer screening by test methods (16,17), supplemented with a more recent meta-analysis on flexible sigmoidoscopy screening (18); and the European Code against Cancer's scientific justification on recommendations for cancer screening (19). Specific literature searches were used for potential new screening programmes for prostate, lung, gastric and ovarian cancers. Current evidence for prostate and gastric cancer screening was discussed at the respective consensus meetings with international experts.

Status reports on the implementation of cancer screening were available from surveys: IARC 2008 (20), EUNICE (21), EuroScreen (22), EU Joint Research Centre (23,24), IARC ongoing (6) and the CanCon cervical cancer screening working group (supplemental information available at the CanCon web site, <http://www.cancercontrol.eu/>). Earlier documents on the concepts and further recommendations on the implementation of cancer screening as a part of cancer control policies were also reviewed: EPAAC documents on planning for cancer control strategies with a section on cancer screening, the curriculum report ESSM (25) and materials EUROCOURSE (26) and the European Science Advisory Network for Health documents and reports (7,27).

Supplementary data on current implementation status of cancer screening programmes in individual Member States, including further organizational details, resources, governance and decision-making processes, legal frameworks, quality assurance and quality management systems, were obtained through the partners and experts participating in the working group meetings for the Work Package on Cancer Screening, held between May 2015 and February 2016. This data collection process obtained information not published in scientific papers. Information was requested on particular achievements as well as bottlenecks and barriers. In the working group meetings, suggestions of relevant topics regarding policy-making were collected.

Recommendations of the guide chapter were drafted by the authors of the chapter and delivered for comments and review within the working group. In connection with the Cervical Cancer Screening Working Group, a survey on governance and legal frameworks was performed for all 35 EU and European Fair Trade Association countries and devolved nations of the United Kingdom (supplemental information available at the CanCon web site; <http://www.cancercontrol.eu/>). Information on this survey in this document is based on answers from the 33 countries that had responded by September 2016.

In the formulation of the general recommendations on governance structures and functions, the publicly available protocols from the United Kingdom, Norway and Sweden, specifically developed to deal with issues concerning national screening programmes, were consulted (2,28,29).

## Governance of cancer screening

Governance and decision-making processes are at the core of well-functioning cancer screening (Fig. 4.1). Governance is here to be understood in the conceptual framework of stewardship as elaborated by WHO (30–32). This implies that the ministries in charge of health assume the ultimate responsibility for the management of the national resources to the health benefit of their entire population by directing the establishment of as good and fair a health system as possible and by promoting health aspects in all policies (33,34). Governance in the health sector refers, therefore, to a wide range of steering and rule-making functions carried out by governments and decision-makers to achieve and develop national health policy objectives. This involves policy development and implementation, detecting and correcting undesirable trends, influencing or regulating health care funders and providers, and establishing accountability mechanisms (e.g. by monitoring and evaluating health system performance). While the scope for governance is usually greatest at the national or legislative level, it also covers the steering role of regional and local authorities, and involvement of stakeholders at all levels is essential.

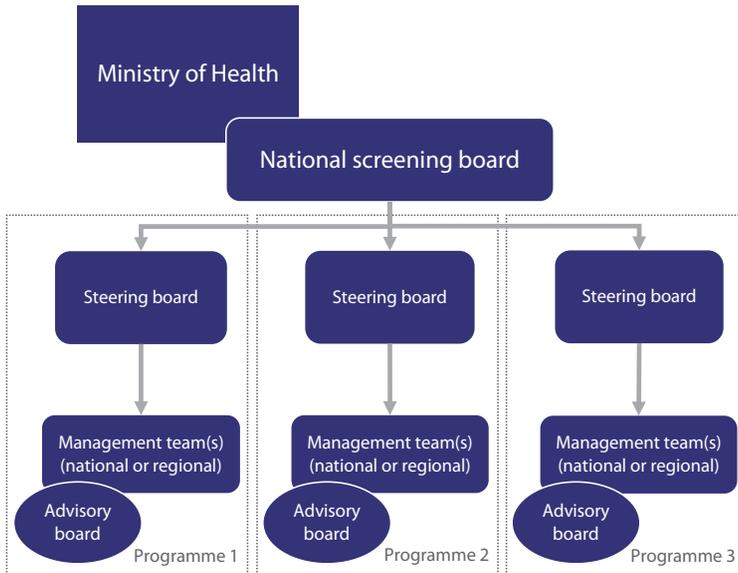
For screening in particular, the national policy-making and governance structure should ensure a thorough and professionally sound procedure for the assessment and introduction of new national screening programmes and for major modifications to, and if necessary the discontinuation of, those programmes. Appropriate legal provisions must be in place and the governance structure should ensure follow-up, quality assurance and evaluation of existing programmes. These requirements are common to all cancer screening programmes and, therefore, governance according to a common general template can be recommended. In what follows, we describe the policy-making and governance structures, legal framework and quality assurance mechanisms that are needed for well-functioning screening programmes.

## Governance structures, policy-making and stakeholder support

Many Member States have found it challenging to implement sustainable screening programmes that fulfil the potential for equitable cancer prevention as recommended by the Council of the European Union in 2003 (20,35–37). The lack of adequate governance and policy-making structures to ensure infrastructure and organizational support appears to be a key barrier (36,37). There are examples where screening programme implementation has failed to produce expected benefits, or has suffered from severe impediments, because necessary organizational, legal, logistic or financial frameworks were not adequately addressed in advance (37,38). In these cases, a more structured approach to governance and decision-making would be beneficial (39).

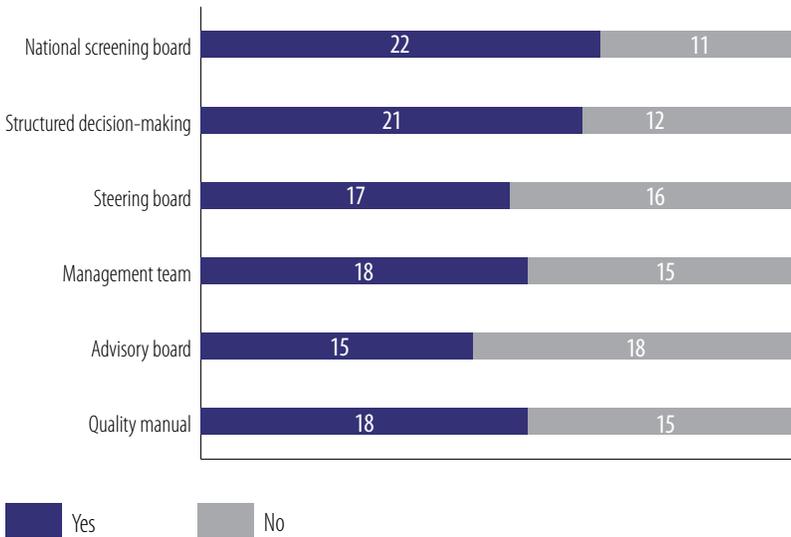
Fig. 4.2 shows what a governance structure can look like covering the key tasks: (i) policy-making, here embodied as a national screening board advising the ministry; (ii) supervision by cancer site-specific steering boards; (iii) management, here performed by one national or several regional management team(s); and (iv) feedback from screening providers and the scientific community through advisory boards or similar organs. All these functions and designated responsibilities should be covered in the governance structure, while allowing considerable adaptation according to the local setting and circumstances. Each of the elements will be looked at in detail below.

**Fig. 4.2** Organizational chart of an example national governance structure



In a small number of countries with successful population-based screening programmes, decision-making and governance structures, tasks and procedures have been formally defined (2,28,29,40). The policy-making and screening governance in the Netherlands provides a good example where the Health Council, which produces scientific advice on health policy, both unsolicited and solicited by the ministry in charge of health, includes a permanent Committee on Population Screening (corresponding to a national screening board in Fig. 4.2, below) (40). The resulting detailed advice includes provisions for the requirements for successful implementation (41). The Centre of Population Screening of the Dutch National Institute for Public Health and the Environment carries out feasibility studies and finances, directs and coordinates implemented programmes. Where an effective monitoring system is in place, the process, costs and effects of new policies, introduced on a small scale under controlled circumstances, can be easily measured and tailored if necessary before general roll-out. Well-developed policy-making and governance structures should also promote the allocation of necessary resources for RCTs and for piloting programmes or modifications as randomized health service studies (42–44). An interim analysis of the results of a survey conducted as part of the activities of CanCon suggests that many European countries lack several components of the governance structure of cervical cancer screening (Fig. 4.3).

**Fig. 4.3 Governance of cervical cancer screening in Europe**



**Note:** The figure summarizes the number of countries reporting the presence of each governance structure component (see the text for definitions of each component addressed).

The EU Council recommendations and the EU guidelines set a common framework for quality-assured screening. Each country has to assess how screening according to these principles can feasibly be organized within their health system and should identify and remedy gaps in the available resources and infrastructure. In countries where domestic experience of effective, well-organized population-based cancer screening is lacking, international collaboration with expert units experienced in coordinating and evaluating screening programmes can be useful or necessary in the planning and piloting phases (25,45). It is not necessary for each Member State to perform all generic health technology assessments independently; collaboration could save significant resources and avoid duplication, for example on choice of test technology. European-level data repositories and the production of standardized quality indicators would also be desirable in that it would promote comparability of programmes, compliance with guidelines and quality of screening across the EU.

### The importance of political commitment

The quality of political decision-making is critical for any public health activity. In the case of cancer screening, this includes a long-term commitment to follow guidelines and to assure quality at all stages of the screening chain (7). Appropriate synthesis of evidence and assessment of baseline conditions such as disease burden and existing and potential treatment capacity are of utmost importance from the outset. Commitment to invest implies expected returns in terms of deaths prevented, quality-adjusted life-years (QALYs) gained and/or downstream treatment costs saved. Political decision-making without commitment to assure quality of the screening process may be detrimental to trust in cancer screening, both in the target population and among professionals, and should be strongly discouraged. A regional or national parliament agreement may be needed in order to assure the long-term commitment.

## **A national screening board to advise decision-makers on national screening programmes**

A designated national screening board, or other such competent entity, should be responsible for advice on policies and decision-making regarding new population-based screening programmes or modifications to existing programmes (Fig. 4.2). The process should be structured and defined in a transparent procedure based on clear, evidence-based criteria to ensure that a proposed new or modified screening programme is able to reach an optimal balance between benefit, harm and costs (by measures capturing the relevant health impacts to a sufficient degree, such as cost per QALY gained). The board should ensure that the necessary organizational, logistic, legal and financial frameworks exist or can be developed. Defining institutional responsibilities, collaboration between the key institutes and consultation with relevant stakeholders allows benefit from existing expertise and broad support and commitment. The decision should be reviewed before each step in the implementation process: feasibility testing, piloting and full-scale roll-out of service screening (Fig. 4.1) (7). A multistep decision-making process is necessary because the performance and outcomes of the proposed screening programme may differ significantly from those demonstrated in controlled trials, as well as from other service settings, and the full impact of these differences may not be evident in advance (43).

## **Programme-specific steering boards: oversight and sustainability**

Once a decision to implement a screening programme has been politically ratified, a programme-specific steering board is required. The steering board oversees both the implementation phases and the sustainability and continuous incremental improvement through the quality assurance processes of the established programme. The steering board should shoulder the executive professional responsibility for the performance, quality assurance and evaluation of the screening programme, including the continuous assessment of the test methods and procedures, and the financial, ethical and legal frameworks. It officially sets and maintains the overall goals of the screening programme. It also ensures that the means and mechanisms are in place to monitor and achieve those goals. It is the forum for resolving political, legal, organizational, technical, cost and management issues that have not been resolved elsewhere. To fulfil its tasks, the steering board must have access to both political and high-level administrative decision-makers, and it must be representative of the key stakeholders, including programme management. The steering board may also decide to submit a proposal for a major modification or cessation of the screening programme under its jurisdiction to the national screening board. The steering board should convene regularly, several times a year.

## **Programme-specific management teams: execution and reporting**

Successful implementation and a sustainable screening programme with integrated quality assurance and the capacity for continuous quality improvement requires a competent management team running the programme on a day-to-day basis at the national or regional level, with a clear mandate from the steering board and the necessary resources to fulfil its responsibilities (see below). These responsibilities include coordination or supervision of all steps in the screening process from identification of the target population to surveillance after treatment of screen-detected cases. It further includes the development and dissemination of information material, collection and validation of monitoring data, regular compilation and linkage with other relevant registers for reporting of performance and outcome of screening, coordination of quality assurance activities, and the further development and continuous quality improvement of

the screening programme according to directions and frameworks given by the steering board. Periodic formal programme evaluation may be tasked to an independent unit in order to avoid self-assessment by the management team. Some responsibilities may feasibly be delegated to the regional and local levels along with the adequate mandates and resources. In federated and larger countries, regions may have their own management teams, but policy should be formulated at the national level. Programme evaluation should also have a national scope.

### **Advisory boards: linking management and providers**

Successful programme management depends on good communication with all screening service providers, and access to their expertise (25). A multidisciplinary advisory board or forum can fulfil these functions by providing representation for the professional groups and institutions that screening delivery depends upon, facilitating the flow of information of issues of current import between management and the screening service providers and advocacy groups, and sharing information with academic and professional societies and institutions. The advisory board to the Norwegian screening programme for cervical cancer, as an example, is a multidisciplinary board including representatives from professional bodies (pathology, clinical cytology, gynaecology, gyno-oncology, general medicine, medical laboratory technology, epidemiology, microbiology) in addition to the Cancer Society and the National Reference laboratory for HPV (46). The appointment of one advisory board member as responsible for equity issues in the screening programme is recommended. Based on the cooperation of the advisory board and the management team, it is advisable to produce a programme-specific quality manual that describes the procedures and protocols that fulfil the quality requirements in that particular programme (47). The local quality manual should be in accordance with the relevant European quality assurance guidelines. Only a handful of countries in Europe have screening programmes with all or most of the governance structure components described in this section. A survey of governance structures for cervical cancer screening in 33 countries showed that countries are often lacking one or more governance component (Fig. 4.3).

#### **Recommendation 4.1**

Successful evidence-based cancer screening needs a competent, multidisciplinary and transparent governance structure with political, financial and stakeholder support.

### **Legal framework for population-based cancer screening**

Population-based screening is a complex undertaking that needs careful coordination and monitoring of performance and outcome. In most cases, a legal framework needs to be developed that is designed to run the health services and to regulate the comprehensive information systems required to manage and to ensure the quality of population-based screening programmes. The legal framework should provide regulation of patient rights, consent requirements, institutional responsibilities, financing and tendering, personal data safety, electronic health records, tissue sampling and biobanking, population and cancer registration, and scientific research and development (12,48).

The legal framework and information systems for population-based screening must secure an adequate balance between fundamental rights of privacy and access to effective, safe, high-quality and cost-efficient health services. Confidentiality of personally identifiable information on health status must be protected while fulfilling the duty to demonstrate and optimize health benefits and minimize negative effects and costs of screening.

## Registration and linkage

Effective screening management necessitates a legal mandate to register centrally all screening, diagnostic and treatment activity with a personal identifier, including negative test results, and to cover both programme-initiated and opportunistic testing. The registration must be sufficiently detailed, of high quality and complete (8,11), which precludes active consent requirements for registration.

The crucial requirement for successful implementation of quality-assured population-based screening is the possibility for linkage of at least population (target group identification), cancer and cause of death (outcome information) with and screening registers (performance information) (12,49). This requires the building of population-based cancer registries where such registries do not yet exist (26). An audit of the screening and treatment histories of all cancer cases arising in the population covered by the screening programme, and comparison of these screening histories with those of population-based controls, provides a possibility of evaluating the effectiveness of the screening programme and yields crucial information on its strengths and weaknesses. Such audits allow rational decisions to be made on modifications to screening policy and protocols, enable repeated incremental improvements to effectiveness and the prioritization of quality assurance efforts. Linkage with other registers such as vaccination and hospital episode registers can also be useful or required for adequate management, monitoring and evaluation. As for registration, such linkages should not be based on active consent. Evaluation based only on consenting individuals are likely to be biased and misleading (50). However, appropriate data protection safeguards should be in place to ensure privacy.

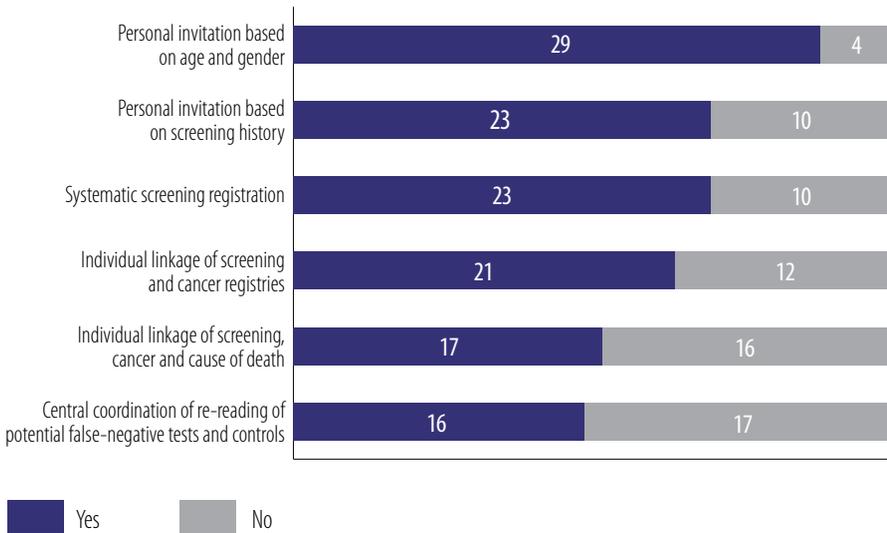
## Invitation and fail-safe monitoring

A population-based screening programme relies on the identification and personal invitation of all those in the defined target population. There must also be fail-safe monitoring to ensure adequate management of those screening positive. Consequently, those managing the screening programme must have access to a current population register with contact information and unique personal identifiers for correct linkage to screening databases and other relevant data sources. Depending on policy, invitations are sent based on a combination of age and screening or medical history. Management teams must, therefore, have the legal mandate to contact people directly based on their screening history with invitations and reminders, and to keep administrative records of this activity.

## Current status of the legal framework for screening in Europe

The lack of an adequate legal framework has been recognized as a major obstacle to effective screening programme implementation in several settings. Nevertheless, data collection and linkage must be in agreement with legal regulations. When legal barriers impede crucial data exchange operations, adaptations of local law may be required. According to results of the survey conducted in connection with the CanCon Cervical Cancer Screening Working Group, there are still significant barriers to many essential functions of population-based cancer screening in Europe (Fig. 4.4).

**Fig. 4.4** Legal frameworks for cervical cancer screening in 33 European countries



**Note:** The figure summarizes the number of countries reporting that their legal framework allows (prescribes in the case of systematic screening registration) each of six operational functions of the screening programme.

**Recommendation 4.2**

The legal code in a country should provide a specific framework for population-based cancer screening, enabling as a minimum the following basic functions: personal invitation, mandatory notification and central registration of complete screening and outcome data, individual linkage to cancer and cause of death registries for appropriate quality assurance, including audits.

**Resources for quality assurance**

Population-based programmes with appropriate quality assurance have not been fully implemented in all Member States since adoption of the recommendation on cancer screening by the Council of the European Union (5). In certain countries or regions, no such programmes exist (6,20,23,25). Integrated quality assurance has proved to be necessary to secure the potential benefits of population-based screening and limit the associated harms and costs. However, earmarked resources are needed for this activity, resources that are not always budgeted in the planning phases leading to implementation of screening. It is crucial to realize that adequate resourcing is a prerequisite for a screening programme, and that it may be better to limit the scope of the screening programme (such as number of lifetime tests) rather than neglect quality assurance if resources are scarce.

Wide variation in practices and effectiveness is observed throughout the EU, and inefficient opportunistic activities still dominate screening in several countries. A recent review on quality assurance standards and programmes in the cervical cancer screening programmes in Europe showed that organized efforts for quality assurance, including auditing, monitoring and evaluation, were carried out to a differing extent and were not standardized (Annex 4.1) (24). Most countries

found it hard to estimate the costs associated with launching and operating the organized programme. Similar systematic information on the routine audit practices of breast and colorectal screening programmes is not currently available. Nationwide, population-based registration of breast, cervical and colorectal cancer is not yet feasible in all EU Member States. In 2012, cancer registry coverage of the combined European populations was somewhat more than 60%, and systematic evaluation of cancer control and quality of care remained modest, except in a few dedicated cancer registries. Evaluation of mass screening programmes was supported more or less routinely by only 44% of cancer registries (51).

Considerable challenges, therefore, remain to bolster health equity. The lack of comprehensive quality assurance in settings relying on opportunistic testing, or even in population-based services, generally results in a less favourable benefit-harm balance compared with screening with integrated quality assurance (20,36).

Components included in comprehensive quality assurance are listed in Box 4.3. Based on the European recommendations (8,10–13), systematic quality assurance requires defined protocols for standard procedures and quality management throughout the diagnostic and patient management services within the programme. In addition, a substantial proportion of the resources in quality assurance are required for well-organized information systems that support the aims of screening registries and population-based cancer registries (10,52). This infrastructure is necessary to systematically audit the programme policies and services, as recommended in the guidelines (10,12). Adherence to these general principles and recommendations on systematic quality assurance is an ethical imperative to assure that the screening services delivered to the population are appropriate (49). Quality assurance also includes timely, prospective evaluations of modifications of existing programmes and for piloting new programmes (8).

**Box 4.3 Functions and budgetary items for the quality assurance allocation of 10–20% of total screening programme expenditure, in accordance with the European guidelines for quality assurance in cancer screening**

- Development and maintenance of well-organized information systems
- Clinical and diagnostic quality assurance and quality management
- Development of population-based cancer registration and other databases for adequate monitoring of the burden of disease and the outcomes of screening
- Development, implementation and enforcement of a quality manual based on European and national standards
- Reporting of performance and outcome indicators based on European and national standards
- Retrospective evaluation of the effectiveness of the programme and its components
- Prospective evaluation and introduction of new screening methods, policies and organizational models

Based on experience in implementing population-based cancer screening programmes in Europe, an estimated 10–20% of total screening programme expenditure should be dedicated to quality assurance (53) (Box 4.3). The lower end of the range, 10%, is more applicable to very large, less complex programmes with substantial economies of scale. In the initial years, this proportion

may be substantially higher because of the low volume of screening examinations compared with the situation after complete roll-out of a nationwide programme. If resources are scarce, a good approach may be to start with a limited target population, with the view to expand when quality is established and resources allow, rather than compromise on quality assurance. Resources spent on quality-assured screening may be largely compensated by the reduction in inefficient opportunistic overscreening and subsequent overtreatment.

A substantial proportion of the resources is required for the development and maintenance of well-organized information systems, reporting the results based on the European standards and related national quality manuals and indicators; for systematic audit programmes of cancer screening; for prospective evaluations required for modifications of existing programmes and piloting new programmes; and for building up cancer registry systems that enable monitoring and evaluation of cancer screening and its impacts on the population. Evaluation of clinical and diagnostic quality irrespective of cancer screening is also very important; there are synergies with this area of research and evaluation of cancer screening programmes. Health equity should be an integrated aspect of the regular quality assurance activities at both programme and patient management levels.

#### **Recommendation 4.3**

Successful implementation of effective cancer screening programmes requires significant resources for quality assurance that is 10-20% of the estimated total expenditure of a full-scale programme.

## **Organizational requirements**

Adequate organization and coordination of screening are important at all stages of programme development from preplanning and feasibility testing to implementation piloting, roll-out and continuous improvement.

### **Organization and infrastructure**

A programme should be thoroughly preplanned for the target ages, screening interval and tests used to identify preclinical disease. Appropriate synthesis of evidence on effectiveness, adverse effects, health-economic aspects, in combination with information on the burden of disease, is essential background information for these tasks. In this phase there should be data also for estimation of the invitational population size per year, planning for feasible schemes to cover the target population often enough (interval between invitations) and plans on how to reach a high uptake of the primary test and guarantee fully quality-assured management services ready at the time of starting.

Population-based cancer screening has infrastructure requirements that need to be verified or developed before starting to screen. First, the target population (age, region, gender) has to be individually identified to allow a call and recall system. For follow-up of screening outcomes, population-based registration of both cancer and screening is needed. Additionally, time and cause of death has to be individually linked with screening invitation information for outcome evaluation purposes. The development of a comprehensive quality assurance plan and manual needs to precede the start of screening activity. Planning includes verification of adequate

capacity through the whole screening chain from individual identification of persons to be invited to treatment and follow-up of screen-detected lesions.

A new programme and all its components, or new procedures in an existing programme, should be feasibility tested and piloted in a controlled fashion before national roll-out (Fig. 4.1). Initial training and development of competence can be focused on a developing national screening reference centre or area, where feasibility testing and piloting can be based, and where subsequent training needs for the roll-out phase can be satisfied. The invitational procedures with call and recall, acceptance of testing, communication with the screened person, delivery of further investigations (e.g. diagnostics and treatment), costs and other details not yet known at launch may provide challenges. For example, the uptake of screening may depend on the premises where samples are taken, opening hours, public traffic, personnel (women for breast or cervical cancer screening), among many other factors.

After the piloting phase, the programme can be rolled out after modifications and corrections deemed necessary based on pilot evaluation. The full implementation of the programme may take several years to achieve coverage and ensure optimal function through the screening chain. A gradual build up is usually needed to ensure practical resources, for example colonoscopy services for those who are positive for faecal occult blood test. Integrated comprehensive quality assurance allows for further incremental improvement in a continuous quality cycle.

A high level of organization with solid governance and coordinating functions also give better opportunities to stop ineffective or harmful activities in a controlled fashion. If existing screening does not fulfil quality requirements, the decision must be either to reorganize by following EU guidelines or ultimately to stop the ineffective programme. Continuation of an ineffective programme is unacceptable.

Modifications from ongoing opportunistic testing (either self-selection or general recommendations as opposed to invitation based) towards population-based programmes are encouraged.

#### **Recommendation 4.4**

Implementation of population-based screening should be a carefully managed multistep process through the phases of coordinated planning, piloting, roll-out and continuous improvement.

## **Coordination**

Following the political decision with associated budget allocations to start implementing a population-based cancer screening programme, and formulation of its goals and frameworks, the first step is to establish coordination and allocate institutional responsibilities. The institution housing the management unit should receive a clear mandate and resources to manage the entire process of programme implementation depicted in Fig. 4.1. The management unit also has to prepare the budget details through all phases, including the resources required for quality assurance, programme management and staff training. The work necessitates close collaboration with authorities and all stakeholders, preferably within a well-defined and mandated governance structure (Fig. 4.2). The mandate may also require changes in national legislation to ensure that it does not contradict effective implementation. Considerable autonomy to take organizational decisions must be allowed for coordination.

## Multidisciplinary management and evaluation teams

It is essential that a screening programme is managed by specialists with adequate knowledge and training in the subject areas of cancer screening. Specific training possibilities in the EU are available. Experience from other EU countries could be helpful; experts from other countries should be involved as consultants if local expertise is unsatisfactory.

Professional expertise should be utilized from the planning phase (development of standards and quality indicators) and throughout the implementation and for continuous evaluation. The professional and organizational management structure must be equipped with the competence and the mandate to control the quality of the entire screening process. Recent European guidelines and available European expertise should be consulted regarding questions on efficacy and effectiveness of new technologies. It may not be necessary to complete a national health technology assessment on questions related to new tests or diagnostic/therapeutic procedures if thorough international evaluations already exist. In that case national health technology assessment agencies could focus on questions related to local implementation and costs.

## Registration and information technology systems

The formation of a centralized data registration system for quality assurance is critical for the success of a programme. The format of the data follows standards developed by professionals and based on the European quality assurance guidelines. Although linkage to the screening procedure reimbursement system is desired, it is essential that the system is not limited to invitation and procedure reimbursement but also covers performance and outcome of the screening programme.

The requirements for continuous quality assurance should be considered early on and incorporated when designing the comprehensive information technology system that covers the entire screening process, including the quality of treatment of detected lesions. The established quality assurance system should also be used for procedures outside the screening programme.

In most EU countries, the screening data platform has not been embedded in a comprehensive clinical health (e-health) data system; however, this would be highly recommended.

### **Recommendation 4.5**

The mandate and resources for screening coordination and training, and for the electronic information systems necessary for quality assurance and incremental improvement, must be secured before starting the population-based screening service.

## Integrated evaluation

### Linkage and indicators for quality and effectiveness

The Council of the European Union recognized that quality screening includes analysis of the process and outcome of the screening, and that this analysis is facilitated if the screening database can be linked to cancer and mortality databases (5). The European guidelines for quality assurance in breast, cervical and colorectal screening (10,12,13) all emphasize data linkage between screening and cancer registries; implementation has, however, been limited throughout Europe (54). In this context, the FP7 European project EUROCOURSE formulated a set of recommendations for data interfaces between screening programmes and cancer registries as well as with other

information sources (26). A set of performance indicators has been generated separately for each screening programme for comparative monitoring at the European level, and the importance of linking the screening data not only with cancer registry data but also with other registries of interest (population, cause of death, diagnostic and treatment registries and, more recently, HPV vaccination and biomaterial registries) has been emphasized (26,48). While the linkage between cancer registries and mortality databases has been established in most European cancer registries, linking the data from national screening databases and cancer registries still poses a significant issue in some (Fig. 4.4).

The Council of the European Union recommendation mentions a need for monitoring specific performance indicators, without detailing the nature of these indicators. The specific guidelines discussed above describe these indicators thoroughly and set the desired levels. For example, in breast cancer screening the desired invitational coverage is 100%, the attendance rate over 75%, the rate of recalled less than 3% and first year sensitivity over 70%. The other approach to assessing performance is the rate of false positives (recalled women whose examinations end with a negative result) and the overdiagnosis rate (breast cancers that would not have come to clinical attention were it not for screening). The estimates from routine screening for the latter vary considerably (1–54%), although it is reduced to 1–10% when adjusted correctly for lead time (55).

#### **Recommendation 4.6**

To secure the benefits of screening, routine linkage between the registries containing relevant data for defining the population, performance and outcome is essential and can be considered an ethical requirement of screening.

### **Monitoring and equity**

Quality management must include both continuous monitoring of the quality indicators and programme improvement when indicated by monitoring or related evaluation projects. Quality assurance should be performed both at institutional and individual level, as appropriate. Linking indicators of quality with reimbursement of screening procedures provides a powerful tool for quality assurance and can initiate mechanisms to provide training and education to professionals failing to reach the minimum quality requirements and to exclude from participation in the screening programme any institutions and individual specialists repeatedly failing to reach agreed benchmarks of quality.

Monitoring and evaluation reports must be published regularly to inform the public and decision-makers and to permit timely modification of programme policy, if necessary (5). Because of the importance of acceptance of the programme by society, the results have to be communicated to the public on a regular basis. Collaboration between countries in monitoring and evaluating routine programmes will ensure better comparability of results and may encourage higher standards in all aspects of quality assurance. Countries with federated screening programmes need central collection of monitoring data for calculation and analysis of performance indicators and their publication and dissemination. An example of such a monitoring organization is provided by the Osservatorio Nazionale Screening (National Centre for Screening Monitoring) in Italy (56).

An important advantage of population-based screening programmes is that they can contribute to improve equity by comparison with other preventive health service modalities such as case finding or opportunistic testing (3). This is achieved by improved access to services through the

personalized invitations to all individuals in the target population and adoption of comprehensive quality assurance of services throughout the programme span (57,58). However, social inequalities in access to cancer screening can still be observed within population-based programmes, evident as lower participation in cancer screening programmes by lower socioeconomic status, within minority ethnic groups or in deprived areas (59–68). Participation in and performance and outcome of population-based screening varies remarkably also between countries (23,35–37,54,69), indicating large inequalities throughout Europe. According to a recent report on breast cancer screening, only about half of the EU Member States monitor access to screening by socioeconomic level, educational level and/or ethnicity/nationality (70). There is also some evidence on the association between cancer burden and human development index, a composite indicator of life expectancy, education and gross domestic product using aggregated data (71–73). Increases in the unemployment rates during the recent economic recession have also been associated with rises in cancer mortality (74).

Evaluation and regular monitoring of screening performance by demographic and socioeconomic groups, and in regions by their development index, is essential to verify whether screening reduces social inequalities in cancer and improves equity in health. Information on socioeconomic and ethnic or language groups, and on issues such as education level can be generated through linkages with appropriate population registries and census records. Evaluation research with experimental designs – also with qualitative components – is needed when social inequalities in cancer have been revealed (68). When attempting to correct social inequalities in cancer screening, it would be very useful to have partners from different countries and programmes with earlier experiences on the relevant interventions. Collaboration and investments in translational research are needed to develop research activities in the local, specific programme settings (e.g. in the case of poor attendance or poor adherence to quality assurance guidelines) on reasons and on how to optimize attendance and to develop balanced, appropriate information for the programme. The Council of the European Union's recommendation (5) already covers most aspects of monitoring content and aims. However, explicit address of social inequalities as an essential part and specific aim for monitoring is added here.

#### **Recommendation 4.7**

Whenever relevant, evaluation and regular monitoring of cancer screening should also detect social inequalities and trigger research and interventions on improved equity in health. Research collaboration has an added value to develop interventions and solutions in the local settings where social barriers and social inequalities in cancer have prevailed.

### **Health economy and benefit-harm balance**

According to the recommendation by the Council of the European Union from 2003 (5), it is an ethical, legal and social prerequisite that cancer screening should only be offered to fully informed people with no symptoms if the screening is proved to decrease disease-specific mortality, if the benefits and risks are well known and if the cost-effectiveness of screening is acceptable.

The balance of benefits and harms is a strongly debated topic, particularly in the field of population-based breast cancer screening. The usually considered benefits from breast cancer screening include avoiding deaths from breast cancer, achieving less invasive treatments and improving quality of life; harms include overdiagnosis, overtreatment, false-positive and false-

negative findings, anxiety, radiation exposure and pain. The recent IARC Working Group (75) stated that there is sufficient evidence of a reduction in breast cancer mortality through screening by mammography in women aged 50–74 years, to the extent that the benefits substantially outweigh the risk of radiation-induced cancer, and of the detection by screening of breast cancers that would never have come to clinical attention (overdiagnosis).

Multiple reviews have been published in this field recently; however, because of differing inclusion strategies and benefit and harm definitions, the benefit-harm ratios vary considerably. For example, for each prevented breast cancer death, one review estimates that 0.5 women are overdiagnosed per death prevented (22), another review that three are (76) and a third that as many as 10 are (77). In the last estimate, lead time was not taken into account (55), which can be done best by including observational time at least 10 years since the last screen or by modelling (75). The EUROSCREEN Working Group (a cooperative group that includes experts involved in planning and evaluating most of the population-based screening programmes in Europe) in its summary of screening outcomes estimated that for every 1000 women (screened biannually from age 50 to 69) seven to nine breast cancer deaths are prevented, four women are overdiagnosed and 200 have at least one false-positive recall (22). While the benefits are usually estimated on historical RCTs and observational studies, the harms are almost exclusively based on current screening practice and the results may differ for various technical, cultural and societal reasons and because of variation in screening performance and breast cancer risk.

Communication of benefits and harms should be central to population-based screening programmes, and those invited should be provided with the information needed to make an informed decision about participation. In a balance sheet for breast cancer screening, the absolute number of lives saved and the number of breast cancer cases overdiagnosed in a given scenario may be presented. No judgement is then made regarding the relative value of a prevented breast cancer death to a case overdiagnosed – this is left for individual judgement.

The current approach for the acceptability of an intervention demands limited adverse effects and substantial positive health outcomes (absolute or QALY gained; improvements to cognitive, motor and/or socio-emotional development; significant increase in management or treatment options) with the effects established with certainty, preferably in RCTs (see below). This should lead to a reasonable ratio between costs and benefits, with the assumptions that the implementation will not lead to substantial unintended effects and that other developments do not change this ratio in the short term (4). The incremental cost-effectiveness ratio indicates the additional cost necessary per QALY gained and can be used as an indicator of cost-effectiveness of new methods in comparisons with already existing ones.

#### **Recommendation 4.8**

Benefits and harms of screening need to be clearly communicated to the public as the appropriate balance may be judged differently by individuals; scientific consensus on the appropriate estimation method and estimate would be of great value.

#### **Recommendation 4.9**

The cost-effectiveness of a programme or a specific modification of it should be evaluated prior to deciding on full implementation; Member States should define a threshold value relevant for decisions on cancer screening, considering affordability and available resources.

## Evidence of effectiveness and harms

The evidence for effectiveness indicators comes from either experimental or observational studies, with experimental studies typically perceived to provide higher-quality evidence based on traditional evidence hierarchy. A recent review, using only data from RCTs on breast cancer screening, has estimated that European population-based programmes achieve a breast cancer mortality reduction of 20% (76). However, the relevance of including breast cancer screening trials run in the 1960s to 1980s should be questioned when assessing current services given the large-scale improvements since then in both mammographic equipment and treatment for breast cancer (75). More recent, high-quality observational studies are considered to provide the most robust data with which to evaluate the effectiveness of mammographic screening (75) and new evaluation trials (e.g. on novel methods) are needed. Mortality reduction estimated from observational studies yields somewhat different results, depending on their design, and these results should be interpreted with caution both concerning the type of design and the possible biases that could be introduced; incidence-based cohort mortality follow-up studies are considered most relevant (75). It should be noted that varying protocols (e.g. infrastructure, technology, personnel, target age, invitational protocol, registration, and availability of data) and actual attendance rate may reflect the level of effectiveness, and that available, high-quality evidence tends to come from higher income countries.

Effectiveness of Papanicolaou (Pap) smear screening for cervical cancer was demonstrated by cohort follow-up studies on cervical cancer incidence and mortality (78), and efficacy trials have become increasingly available for novel methods such as HPV testing (8,79,80).

For colorectal cancer screening, recent RCTs have demonstrated efficacy of sigmoidoscopy screening; corresponding trial-based evidence on current immunochemical faecal blood tests, which have improved clinical accuracy compared with guaiac-based faecal occult blood testing, is not available (13,17–19). Efficacy of screening with the guaiac-based faecal blood tests has been demonstrated from RCTs (16) and there are two mortality studies on routine screening programmes using this test system (81,82). In the first study, there was a 10% relative reduction in colorectal cancer mortality in a routine screening programme in Scotland for those invited for screening, rising to 27% for those who completed the test (81); the second study did not find any effect in a randomized health services study in Finland (82). In both studies, the follow-up times are still rather short. Information on the effectiveness of the colorectal cancer screening programmes started during the 2000s and so appropriately long follow-up time is not yet available.

### **Recommendation 4.10**

Indicators for quality and effectiveness based on most recent evidence-based reviews should be monitored for informed decision-making and acted upon regularly by updating the screening programme.

## Potential new cancer screening programmes

### Criteria for implementing cancer screening

The current criteria for new cancer screening programmes (for primary sites other than breast, cervix and colorectum) or for programmes utilizing completely new screening methods that

are not understood as modifications to the current method include synthesis of the evidence of effectiveness: benefits, harms and their balance. The overall benefits should outweigh the expected side-effects and the harm, and the potential programme should satisfy the requirements of cost-effectiveness, based on evaluations from appropriate RCTs (3–5). To gather the required evidence, the Council of the European Union has also recommended that such trials need to be actively run and has proposed also pooling of relevant trials from representative settings in order to help with evidence assessments. Once evidence exists to support these criteria, implementation research in each country is needed to assess the feasibility of fulfilling the national requirements in practice (Fig. 4.1).

So far, evidence on the above aspects has not been considered adequate in the EU to recommend screening for cancers other than breast, cervix and colorectum. Yet only a few such trials and/or pooling exercises have been carried out. The potential to gain further improvement in cancer control through new cancer screening programmes is vast. This section deals with current information from trials on potential new cancer screening programmes for four cancer sites (prostate, lung, stomach and ovaries). These are used as examples to highlight key policy-making aspects. There are also other primary sites potentially relevant for screening and prevention interventions for which no or few trials are available.

### Key criteria for a decision whether to implement

Based on criteria for screening of WHO and others (1,3,4), it can be concluded that there are three key criteria for deciding whether a screening programme should be adopted: (i) is there evidence for the effectiveness of screening; (ii) is there evidence that the benefits of screening outweigh the harms; and (iii) is screening cost-effective (4). These three steps will be described in more detail below. The remaining criteria are relevant for the subsequent process of implementation, monitoring, evaluation, affordability and sustainability of the programme. In addition to evidence criteria, other aspects affect policy-making, such as prioritization because of the burden of disease, feasibility, affordability and availability of resources to organize the programme adequately. These are important in the national decision-making context, but are not discussed further here.

#### **Step 1: effectiveness**

The first step is to determine whether screening is effective, that is, does it reduce mortality from the target disease. This can only be done by means of RCTs with disease-specific mortality as the primary end-point. Observational studies (case-control studies or cohort studies) should be interpreted with caution since they are prone to selection bias: because individuals participating in screening are almost invariably healthier than those who do not, they are likely to have better outcomes, even in the absence of screening. Studies comparing survival rates between screen-detected and clinically detected cases are hardly informative, since in addition to selection bias they are prone to two other forms of bias: lead-time bias and length bias. As a result, screening seems to prolong survival even if it does not extend life.

Because cancer is just one cause of death and because of the inherent time lag between a screening intervention and its effect on mortality, RCTs evaluating screening have to be large and follow-up has to be long. As a result, screening trials are relatively expensive. Still, it is important to realize that they are indispensable. No alternatives (e.g. by using proxy end-points and/or simulation) are acceptable as primary evidence on the effectiveness of a new screening programme (83,84).

### **Step 2: benefit-harm ratio**

The second step is to determine whether the benefits of screening outweigh the harms. A frequently used method to value the health effects of screening is by using utility weights. These weights correct the time spent in a certain disease state for the quality of life experienced in that state. The valued effects can be summed up as the number of QALYs gained. Possible benefits of a screening programme are a reduction in disease-specific mortality or all-cause mortality, a reduction of advanced disease and aggressive treatment, and QALYs gained. Possible harms of screening are pain and stress of the screen test and diagnosis, false-positive tests results, more life living with the knowledge of the disease, false reassurance, overdiagnosis, overtreatment and treatment-related adverse events (4,83,84).

### **Step 3: economic evaluation**

The third step is to determine whether the effects of screening justify costs. The basic economic problem states that wants are infinite, while resources are limited. This problem, scarcity, implies that choices on how to deploy resources have to – and will be – made. All choices involve a trade-off. If a government decides to use resources to implement a national colorectal cancer screening programme, it may not have sufficient funds to simultaneously implement HPV vaccination for adolescent girls.

In general, three types of economic evaluation are distinguished: cost-effectiveness, cost-utility and cost-benefit. For all types of evaluation, the costs of screening, diagnosis and treatment have to be determined. Screening is regarded as cost-effective if the costs per QALY gained are lower than a predefined cost versus effectiveness threshold. A threshold of €20 000 or €30 000 per QALY gained is often used in Europe. National values vary and there are countries, particularly within the middle-income settings, where national values have not been formally decided. The threshold in some countries (e.g. in North America) is higher than in Europe.

While RCTs are indispensable for evaluating screening, they have their limitations. First, RCTs are relatively expensive and time consuming, limiting the number of RCTs that have evaluated screening. Second, RCTs usually have a limited follow-up time. As a result, they cannot be used to determine lifetime health effects and costs, which is necessary to directly determine the cost-effectiveness of screening. Third, the effectiveness of screening might differ between settings. Sources for variation in the results include background risk, quality and costs of screening and management in a given health care system, use of services outside the screening programme and methods in the health-economical evaluation itself. Decision models provide a useful tool to extrapolate evidence from RCTs and address the question of which screening strategy is optimal given local conditions, life expectancy, costs, resource availability and population preferences.

No detailed criteria for assessing health-economical methods or for relevant thresholds when using a given methodology have been included in the above references (1,3,5). WHO-CHOICE has suggested classifying interventions as cost effective if they yield one healthy year of life for one to three times the gross domestic product per capita and very cost effective if below the gross domestic product per capita (85). However, these thresholds are arbitrary and do not address budgetary constraints that may force a choice between several “cost-effective” interventions. The resources available for health care vary greatly between EU Member States, as reflected by an almost seven-fold difference in national gross domestic product per capita in 2014 between

Member States when corrected for purchasing power (86).<sup>1</sup> Health care expenditure per capita varied from €400 to €5500 (87). The national choices for the threshold values for cost-effectiveness vary as a result of variation in the resources available for health care. There is no common threshold value proposed for the EU. The health care resources should be taken into account in the health-economical and inequity analyses and when preparing European-level recommendations.

## Screening for prostate cancer

The current evidence is that the European Randomized Study of Screening for Prostate Cancer has showed that screening using levels of prostate-specific antigen (PSA) results in a 21% prostate cancer mortality reduction in an intention-to-treat analysis (88–90). The trial efficacy point estimates varied between participating countries because of differences in length of follow-up, underlying test and referral rates and contamination for PSA in the control arm. No mortality difference was found after a median follow-up of 11 years in a trial in the United States, failure to do so likely attributable to heavy contamination of the control arm (91,92). Although there are particularly concerns on the harms of overdiagnosis and overtreatment resulting from screening (93,94), it has been shown, based on the European trial results, that the benefits still outweigh the harms (95). Based on assessment utilizing the European Study results on cause-specific mortality, the cost-effectiveness of a screening programme with three screens at age 55–59 years with a two-year interval is at US\$ 45 600 and with four screens at age 55–67 years with a four-year interval at US\$ 92 000 (96). Cost-effectiveness with a single screen at age 55 years was estimated at US\$ 31 500. These cost-effectiveness ratios apply to health care costs as incurred in the United States and may be lower in European settings. For the Netherlands, cost-effectiveness has been estimated at €19 000 per QALY (H. de Koning, personal communication). In future, further improvements are expected because of more use of active surveillance and improved discrimination between indolent and significant disease through use of new biomarkers and magnetic resonance imaging (97–99). Hence, in some wealthy settings with a considerably high threshold value, the cost-effectiveness criteria for some policy options may already be satisfied based on current knowledge. In less affluent countries with less available money for health care, affordability issues and the prioritization of several potentially cost-effective health care interventions certainly need more deliberation before decisions can be made.

## Screening for lung cancer

In the RCTs on lung cancer screening published in the United States, the study populations at baseline consisted of current tobacco smokers or ex-smokers. In a large trial on chest radiography, no effect on lung cancer mortality by chest radiography in comparison with non-screened controls was reported (100). In another large-scale trial on low-dose computed tomography compared with chest radiography screening, annual screening was associated with a 15–20% decrease in lung cancer mortality and about a 7% reduction in overall mortality (101,102). Possible associations of lung cancer screening with smoking behaviours after screening have not been assessed systematically (103). There are several trials ongoing or under follow-up in European countries (104,105). Some variation in the nodule management protocols and of the definition of the high-risk population expected to benefit from screening may translate into variable results on efficacy. Risk

<sup>1</sup> Variation by the gross domestic product per capita ranged in 2014 from US\$ 7800 (Bulgaria) to US\$ 56 100 (Denmark) and US\$ 111 700 USD (Luxembourg), with the average in the EU approximately US\$ 35 000 (87).

stratification is important in lung cancer screening because nodules detected in those without important risk factors tend to be of low malignant potential. A recently reported Italian trial did not provide further support on efficacy of lung cancer screening, but the statistical power was very limited (106). The largest European trial, the "Nederlands Leuven Longkanker Screenings Onderzoek" (NELSON), examined the impact of low-dose computed tomography screening in association with active intervention to quit tobacco smoking (107,108). Outcome results are not yet available. The harms of lung cancer screening include false-positive results, complications from invasive follow-up and overdiagnosis with associated overtreatment. Performance characteristics of screening tools, particularly specificity and false positives, are associated with the algorithms and protocols (109). In the currently available health-economical assessments, the cost per QALY gained in annual screening with low-dose computed tomography in the tobacco-related risk groups has been estimated to vary between about US\$ 13 000 and US\$ 81 000 (110–112). At present, the high referral rates seen in the United States do not seem feasible in Europe, and mortality results are, therefore, needed from the European trials with lower referral rates.

## Screening for gastric cancer

The screening strategies for gastric cancer are targeting different lesions and conditions: (i) screening for gastric cancer itself by endoscopy or fluoroscopy, (ii) screening for precancerous lesions by detecting the ratio between pepsinogen I and II or other biomarkers in the circulation, and (iii) screening for *Helicobacter pylori*, the major carcinogen for gastric cancer, with the aim to eradicate it in those testing positive (search-and-treat strategy) (113,114). The results of randomized trials, performed mainly in Asian countries with a very high background risk of gastric cancer, indicate that *H. pylori* eradication lowers gastric cancer incidence by 30–40% (78,115,116). Endoscopy screening has been suggested to be cost-effective only in high-risk areas of Asia (117,118). The accuracy of pepsinogen testing alone is restricted for precancerous lesion (atrophy) rather than for gastric cancer detection (119–121); furthermore the sensitivity for detecting either precancerous lesions or cancer is limited. Search-and treat in healthy asymptomatic adult populations has been suggested to be cost-effective by considering the reduction of gastric cancer-caused burden as well as other diseases related to this microorganism (122–124).

However, the potential long-term adverse effects have not been considered sufficiently. At the population level, a programme of population screening and treatment for *H. pylori* with antibiotics could plausibly increase the prevalence of antibiotic-resistant pathogens within the community (125). Furthermore, strategies for the age groups to be subjected for eradication are not well defined. Uncertainties remain about the generalizability of results on various strategies and about the benefit-harm balance of programmes applied in community settings. The IARC has therefore recommended exploring implementation of population-based *H. pylori* eradication strategies by the means of well-designed implementation studies, such as the GISTAR study in Europe (78,126). In European populations, the rationale for endoscopy and serology screening for gastric cancer and the associated risk-lesions require more research. Additional clinical trials should help to clarify whether and how to implement population-based *H. pylori* screening and treatment programmes. Support to these trials is key to develop European cancer control policies.

## Screening for ovarian cancer

The poor prognosis for ovarian cancer has motivated initiating screening research. Cell-surface glycoprotein CA125 has been reported to be elevated prior to clinical diagnosis of primary and recurrent ovarian cancer (127). A randomized trial of screening with CA125 in postmenopausal women of average risk demonstrated a survival benefit for those with ovarian cancer (128). Two large-scale trials have reported their results on mortality outcomes and adverse effects of CA125-based screening for ovarian cancer. Among women in the general United States population, simultaneous annual screening with CA125 and transvaginal ultrasound, compared with usual care, did not reduce ovarian cancer mortality (mortality relative risk, 1.18; 95% confidence interval (CI), 0.82–1.71) (129) but about 15% of women with surgical follow-up after a false-positive screening test did experience serious complications. In the United Kingdom Collaborative Trial of Ovarian Cancer Screening, the primary analysis of ovarian cancer mortality gave a cancer-specific mortality reduction of 15% (95% confidence interval, 3–30;  $P = 0.10$ ) over a 15-year follow-up for screening with annual multimodal screening with repeated serum CA125 interpreted with use of the Risk of an Ovarian Cancer algorithm; and a cancer-specific mortality reduction of 11% (95% confidence interval, 7–27;  $P = 0.21$ ) for screening with annual transvaginal ultrasound screening compared with no screening (130). Although the mortality reduction was not significant in the primary analysis, a significant mortality reduction was observed for the multimodal screening when prevalent cases were excluded. The authors concluded that there was also some encouraging evidence of a mortality reduction in the late years of the follow-up period, and further follow-up is still needed before firm conclusions can be reached. False-positive surgery was less frequent in the multimodal screening than in the transvaginal ultrasound screening (131) or using a fixed cut-off for CA125 (132).

### **Recommendation 4.11**

Quantitative estimates of the benefits, harms and cost-effectiveness of possible new cancer screening programmes are needed to decide on implementation. It is essential that the EU Member States finance randomized trials designed to produce the information necessary for policy-making, and investments are needed so that results become available in as early a phase as possible.

### **Recommendation 4.12**

Active European research collaboration and pooling of results from RCTs and related health-economical assessments are necessary in order to obtain evidence relevant for the different settings, with potential variations in the burden of disease, health priorities, effectiveness, and resources and affordability, found among the European countries.

## Summary and conclusions

Most EU countries are planning, piloting or implementing population-based screening programmes for breast, cervical and colorectal cancers. However, there are deficiencies and barriers in many of these programmes, as indicated in a recent implementation report (6), for example in access to screening and in systematic quality assurance throughout the screening chain. Challenges in screening implementation are related in early phases to issues in planning and gradual well-controlled introduction of currently recommended programmes in regions or settings where effective and cost-effective programmes do not yet exist; in later phases challenges relate to modifying and reorganizing currently running programmes with new tests, treatments, policies or working models (Fig. 4.1). Developing key strategic tools on evaluations needed for policy-making on possible new cancer screening programmes (other than for breast, cervical or colorectal cancer) is also essential.

Considerable deficiencies in the governance structures of population-based screening were identified during the development of this chapter (Fig. 4.3), which may severely impede the full implementation of effective population-based cancer screening programmes in Europe. Key functions of screening governance are to secure political and professional commitment to an agreed screening policy with common targets; adequate legal, financial and organizational frameworks and resources to coordinate, evaluate and continuously improve the programme; and a transparent and well-informed decision mechanism for starting, modifying or stopping population-based screening (Recommendations 1–3).

Coordination of a multifaceted screening programme with a number of stakeholders by a competent management team needs to be established immediately following the decision to implement. The management is responsible for the planning and organizing of feasibility studies, piloting, roll-out, training of staff, development of information technology systems capable of population-based invitation and monitoring, comprehensive quality assurance functions and manuals in collaboration with the clinical specialties (Recommendations 4.4 and 4.5). This work starts in the preplanning phase of programme implementation and continues through to the continuous quality improvement of the established programme (Fig. 4.2). Recognition of the human and financial resources needed for this activity is important at the point a decision is made to start a programme.

Routine monitoring and evaluation of the performance and outcomes of screening can be considered an ethical imperative of population-based screening, and allow its maintenance and gradual quality improvement (Recommendations 4.6 and 4.10). The ability to individually link screening and cancer records is required. In addition to continuous quality assurance, essential parts of population-based screening are periodic evaluation of the effectiveness, benefit-harm ratio and health economy of screening; prospective evaluation of new screening methods; and dissemination of the results (Recommendation 4.8). There is a continuing need to develop further research and interventions to ensure equal access to quality screening, irrespective of socioeconomic status, ethnic background or domicile (Recommendation 4.7).

There is untapped potential for cancer prevention through extending population-based screening to new cancer sites beyond breast, cervix and colorectum. However, solid evidence on the effectiveness of new programmes from randomized trials is needed. These trials are necessarily large, time-consuming and, therefore, relatively costly; hence financing mechanisms through pan-European cooperation are recommended (Recommendations 4.11 and 4.12). Such

cooperation is particularly relevant since cost-effectiveness can vary between disparate regions of Europe and cannot always be directly transferred across different economic, epidemiological and organizational settings. At present, evidence on the effectiveness of prostate cancer screening is available; evidence on lung cancer screening is expected in the near future, but acquisition of evidence is still in its infancy for other cancer sites. All new potential cancer screening programmes require investment in research on optimal strategies for acceptable benefit-harm ratios and cost-effectiveness in different settings (Recommendation 4.9).

Cost-effective screening programmes need good governance, monitoring with standard key indicators throughout the screening chain and evaluation of outcome. Establishing sustainable models for funding is still in focus in many Member States. The wide variation in resources for health care between Member States should be taken into account when planning for Europe-wide recommendations and research strategies. Cancer control plans provide an essential mechanism where these issues can be elaborated and integrated into the planning and development of the health service.

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## Annex 4.1

A review on quality assurance standards and programmes in cervical cancer screening programmes in Europe provided data on case audit and its use in 10 out of 19 EU countries or regions (Table 4A.1).

**Table 4A.1** Cervical cancer case audits occurred in cervical cancer screening in 10 out of 19 EU survey respondent countries or regions

Country	Audits	Results used programmatically	Notes
Denmark	Yes	Not specified	National numbers will be published for the first time in 2014, with data from the year 2013
England	Yes	Yes	Audits are completed annually; the results are used programmatically with the aim being to monitor and improve the programme locally
Finland	Yes	No	Audits have been completed through research projects but not regularly scheduled within the programme; results have been used for laboratory quality assurance and policy discussions
Hungary	Yes	Not specified	Audits are completed and published by the National Audit Office
Ireland	Yes	No	Audits are completed through ongoing incident case review with the aim of determining why the cancer developed and to inform any necessary improvements to the screening programme; results are not made public
The Netherlands	Yes	No	Audits completely annually, results have yet to be used programmatically and are not available to the public
Scotland	Yes	Not specified	Audits have been completed at the regional level and a national pilot has been underway since 2011; results are collated annually, used locally and made public in regional annual reports
Slovenia	Yes	Yes	Audits are completed annually and results presented in programme training days and will be published in the next programme report
Sweden	Yes	Yes	Audits have been completed through research projects with the intention of making them annual; results are used programmatically through the regional cancer centres and professional organizations
Wales	Yes	Not specified	Audits are completed ongoing, with results disseminated in local meetings and through direct communication; results have been used for educational and service improvement

Source: Elfström KM et al. Cervical cancer screening in Europe: quality assurance and organisation of programmes. *European Journal of Cancer*, 2015;51(8):950–968.



# Integrated cancer control: the case for comprehensive cancer care networks (CCCN)

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## Introduction

The rapidity of change in the cancer landscape must be considered when pursuing the objective of cancer control in the 21st century. First, the cancer incidence in Europe is continuing to increase, in large part for demographic reasons as the age distribution of the population has shifted upwards. Second, improvements in technology make cancer diagnosis possible earlier, but sometimes at the cost of false diagnosis or overdiagnosis. Third, management protocols are changing all the time, not only through availability of new and better targeted drugs but also through immunotherapy approaches finally becoming successful and advances in imaging techniques, surgery, radiotherapy and other locoregional approaches. Many of these advances come at a high cost, as they may require providing very expensive drugs or substantial investment in new equipment using more advanced technology. Fourth, advances in understanding the molecular basis of cancer have revealed that cancer is much more heterogeneous than it was thought to be hitherto: in the end, each tumour is defined by the set of (somatic) mutations that have caused it and this has direct implications on how that tumour ought to be managed (i.e. personalized cancer medicine). Last but not least, there is increased recognition that supportive treatments, ranging from palliative care to psychosocial-oncology, must be part and parcel of the management of cancer patients.

In view of these changes, it is imperative to consider whether and what actions are needed to improve how cancer control is structured, for two main reasons: (i) cancer control can be improved, but it should be improved in a cost-effective way and (ii) improvements in outcomes must not be confined to a select few but should be for the benefit of all those who are affected. Outcomes must be measured at the population level, with the aim of reducing present-day inequalities (1), and ideally eliminating them. Since the landmark Calman-Hike report in the mid-1990s (2), networking and formalized collaboration between health care providers is increasingly recognized as an option for delivering cancer services (3,4).

Currently, cancer control is organized in different ways in different countries, not uncommonly even within different regions of the same country. Prevention, screening programmes and management of patients may be carried out by the same institution or by different institutions. Various existing cancer care patterns may be influenced by history, by population size and density, by the geographic distribution of the population, by the health system structure and resources available, or by past and present policy decisions. As long as a system functions well, provides optimal outcomes and is cost-effective, there is no reason to change its basic structure; if different approaches serve the purpose of cancer control, there is no reason, in principle, to impose the same modalities everywhere. However, in most systems there is room for improvement.

Today in Europe many cancer patients are treated in general hospitals, whether public or private, and/or in institutions specialized in cancer management, including those that have become known as comprehensive cancer centres. A consistent and broadly applicable definition of a comprehensive cancer centre does not exist, but the Organization of European Cancer Institutes in its voluntary-based accreditation procedure lays emphasis on a wide range of elements, including infrastructure for cancer care, human resources, clinical care activities, research activities, education and institutional structure (5). In the United States, the National Cancer Institute (6) recognizes that a comprehensive cancer centre is a centre that carries out “cancer research and provide services directly to cancer patients. Scientists and doctors at these centres do basic laboratory research and clinical trials, and they study the patterns, causes, and control of cancer in groups of people. Also, they take part in multicentre clinical trials, which enrol patients from many parts of the country. Comprehensive Cancer Centres also give cancer information to health care professionals and the public.”

A comprehensive cancer centre implies a concentration in one location of qualified oncology-dedicated staff; volumes of patients sufficiently large to produce economies of scale; adequate numbers of patients with less common tumours that require special expertise; ongoing opportunities for keeping all personnel up to date; ability to design and to run clinical trials; expertise in epidemiology, oncology and cancer research in various areas; and facilities for data management. Importantly, the superiority of such centres in terms of treatment outcomes (or of specialized similar entities embedded in large hospitals or specialized units) has been well documented (7,8).

This chapter explores a model of integrated cancer control that reconciles the expertise of high-volume specialized referral centres with the greater accessibility of general hospitals, other health care institutions (e.g. imaging centres, community care centres) and primary care professionals (PCPs, e.g. GPs, home nurses and others). Networking models are attractive in principle because, by fostering communication and collaboration, they can both draw on the experience and the abilities of the constituent units, thus implementing synergies, and significantly reduce geographical inequalities by having multiple entry points and by offering cancer control services to the entire population living within a certain area.

Here we outline the features of one particular type of highly integrated network, the Comprehensive Cancer Care Network (CCCN). This chapter describes how CCCNs can be planned and established, how they work and what purpose they serve. It also includes policy recommendations that may prove useful for countries and stakeholders active in cancer networks.

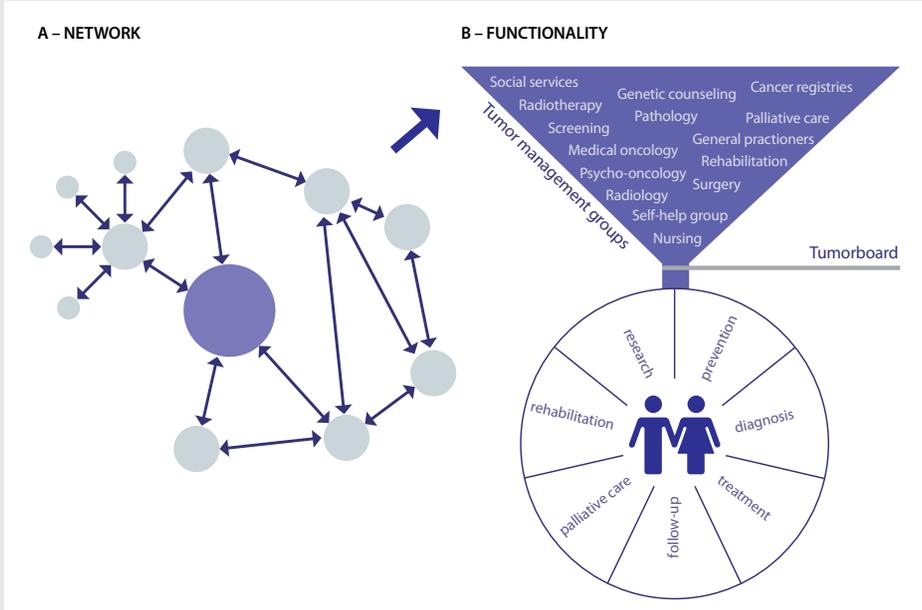
Since different people/agencies may mean different things by the word network, here we have agreed, after extensive discussions and deliberations, on the following definition of CCCN (Box 5.1).

**Box 5.1 Definition of a CCCN as used in this volume**

- A CCCN consists of multiple units belonging to different institutions dedicated to research, prevention, diagnosis, treatment, follow-up, supportive and palliative care and rehabilitation for the benefit of cancer patients and cancer survivors. The key elements defining a CCCN are illustrated in Fig. 5.1.
- These units<sup>a</sup> interact and have a formal agreement to work together in a programmatic and structured way with common governance, in order to pursue their goals more effectively and efficiently through collective synergies.
- Within the CCCN the care of patients is the responsibility of interprofessional teams that are multidisciplinary and tumour specific. Each team or tumour management group works together for the benefit of patients with that particular type of tumour.
- Within the CCCN all units work together and adopt uniform standards of care for cancer-specific pathways that are binding for the entire network.
- The CCCN promotes a uniform system of quality assurance; and a unified informatics system for optimal exchange of information.
- The objective of a CCCN is to provide comprehensive cancer care to all the people living in a certain geographic area, thus pursuing equality and the improvement of outcomes and quality.

<sup>a</sup>The word unit is used to designate any component of a CCCN, whether an entire pre-existing institution or a part of an institution. For example, a unit might be an entire cancer centre, an oncology department of a general hospital or a children's hospital, a mammography facility, a pathology laboratory carrying out mutation analysis or a hospice.

**Fig. 5.1** The key elements defining a CCCN: (A) example of a network; (B) tumour management groups



**Legend**

A – Network: The dots represent units/institutions (e.g. primary care, community hospitals, university hospitals, psychosocial counselling etc.) dedicated to research, prevention, diagnosis, treatment, follow-up, supportive and palliative care and rehabilitation, which work together as a CCCN in a structured way with a common governance

B – Functionality: The tumor management groups within the CCCN are inter-professional, multi-disciplinary and tumor-specific; with the objective to provide comprehensive cancer care to all the people living in a certain geographic area

**Notes:** The example of a network (A) has arrows to indicate the flow of patients, expertise, data and so on between networking institutions of different sizes, with different roles and at different levels in the health system. These work together in a structured way with a common governance. The dots indicate units/institutions (e.g. primary care, community hospitals, university hospitals, psychosocial counselling) dedicated to research, prevention, diagnosis, treatment, follow-up, supportive and palliative care and rehabilitation. In tumour management groups (B), care-related activities are interprofessional, multidisciplinary and tumour specific. The objective is to provide comprehensive cancer care to the entire population within the catchment area.

## Methods

### Surveys

As a preliminary to proposing a specific type of network as a possible model of cancer care organization, we thought it was appropriate to survey what already existed across Europe. A survey collected specific items of information from representatives of EU health authorities, cancer societies, directors of comprehensive cancer centres, cancer registry directors and others. Since a pilot CCCN study is currently ongoing in the Czechia as part of CanCon Work Package 6 (see below), this country was not formally surveyed. Of the remaining 27 EU countries 25 responded (see supplemental information at [www.cancercontrol.eu](http://www.cancercontrol.eu)).

A survey was also carried out to assess how rare cancers are cared for in various countries, as a collaboration of RARECAREnet with CanCon; more specifically, the survey aimed to understand how centres of expertise for rare cancers are being identified in EU countries and how they actually operate.

The surveys consisted of semi-structured interviews with international experts who have a significant role in governance and organization of cancer networks in their respective countries (supplemental information provided at [www.cancercontrol.eu](http://www.cancercontrol.eu)). This served to obtain information on the decision-making process that led to the establishment of a specific cancer care model.

### Literature search strategy

Three strategies were employed for the literature search.

- Relevant literature published in peer-reviewed journals and/or grey literature was identified through systematically searching of medical databases such as PubMed (including Medline, Medical Literature analysis and Retrieval System Online), Google database, Scopus and Web of Science until November, 2015; the exception was "Palliative care" where the literature search was conducted until March, 2016. Boolean operators "AND" and "OR" were used as deemed relevant (supplemental information provided at [www.cancercontrol.eu](http://www.cancercontrol.eu)).
- Cancer network, government and regional web sites were also searched for relevant reports. Articles related to organizational structures in the form of networks (i.e. CCCNs or similar) in Europe were of particular interest and there was a focus on articles discussing organizational structure of CCCNs in Europe.
- A basic exploratory online database search combining the search terms "travel distance" AND "cancer" (no further restrictions) was used to examine territorial inequalities in access to cancer care.

For describing CCCN characteristics and functions, a search of PubMed was conducted using the following keywords and phrases: "cancer control", "cancernetwork", "structure", "infrastructure", "governance". Moreover, cancer network web sites and cancer control organization reports were consulted using the main following keywords in various combinations: "comprehensive", "translational", "cancer", "network", "research", "infrastructures", "outcomes".

In order to find literature and examples for care of cancer patients in interdisciplinary networks, a search was conducted a search using the following keywords and phrases in various combinations: "cancer", "quality of care", multidisciplinary\*, interdisciplinary\*, multiprofessional\*, interprofessional\*, "tumor management group".

For “Palliative care”, the search strategy for Medline database, which used both text words and MeSH/EMTREE terms, was “palliative care AND network AND cancer AND organization”.

For organizational aspects of cancer research and their link to cancer care outcomes the searched was for the words “comprehensive”, “translational”, “cancer”, “Network”, “research”, “infrastructure”, “outcomes”.

The search was supplemented by reviewing references in the retrieved articles and by searching the authors’ other publications. Because of space restrictions, more recent publications were given priority over older ones, and results were narratively reported to mirror the various dimensions of the issue.

## Results

Results from a 2015 survey in which 25 EU Member States participated (see supplemental information provided at [www.cancercontrol.eu](http://www.cancercontrol.eu)) indicated that cancer networks do exist in many countries, as institutions share expertise and facilities for cancer services, and that networks can adopt various configurations that may fit the context of individual countries. In some cases, a network evolved from or was built around one or two specialized centres (comprehensive cancer centre or similar) that may coordinate research and services throughout a region or throughout the whole of a smaller country. Elsewhere, nationwide specialized cancer networks coexisted with regional networks encompassing health care institutions (e.g. general hospitals, specialized centres) as well as primary care. The survey moreover suggested that the notion of integrated cancer networks (whether at national or regional level, or whether with a hub & spoke pattern) is gaining ground in response to the needs of contemporary oncology (supplemental information provided at [www.cancercontrol.eu](http://www.cancercontrol.eu)). In some cases, this notion was expressed in strategic cancer policy documents, whether integrated cancer networks were already at the implementation stage or were yet to be decided upon and formalized. Despite this variety of approaches across regions and countries, networks have in common that they seek to improve and to integrate cancer services, as well as clinical research (8). It emerges from the survey that all the cancer networks included had at least one of the following elements: (i) a formal structure that identifies governing bodies and their respective functions, (ii) multidisciplinary tumour-specific boards that operate according to agreed treatment protocols across the network, and/or (iii) cancer care pathways where named coordinators are responsible for making sure that each patient is seamlessly supported along the pathway at the clinical, psychological and administrative level.

In what follows, the key aspects of CCCNs – their purpose, structure, organization of care delivery and the role of research – will be discussed in more detail, followed by the description of the experiences from a recent CCCN pilot project.

## Building a CCCN

### Main purpose and decision-making

Inequalities in cancer care exist throughout the cancer continuum. Current evidence suggests that incidence rates and mortality rates from cancer differ across society. There is a higher cancer incidence in the most deprived compared with the least deprived 20% of the population. In

addition, for all cancers combined, patients from the most deprived group were more likely to die from their cancer, within five years of diagnosis,) than those from the least deprived group (the difference being as much as 40%; or 27% if adjusted for cancer type (9).

A specific cancer inequality that may be effectively addressed by CCCNs is territorial inequality in access in general and in access to high-quality care in particular, for example represented by inequalities in travel distance to quality cancer care. Territorial inequalities in access to care (i.e. differences in opportunities to receive quality care depending on where you reside, for example due to variable distance from residence to the site of delivery of care or because of local variation of care quality) are a global issue and as such persist with regard to cancer control in the EU Member States. Often these territorial inequalities conflate in one way or another with other social determinants of health; for example, people of higher socioeconomic status have better opportunities to compensate for longer travelling distances to a higher-quality care centre because they can afford transportation to and from facilities or to pay more to live closer to high-quality care. This issue relates to the cancer equity policy paper in that this addresses the issue of inequality in cancer more broadly and to Work Package 7 (community-level cancer care; see Chapter 6), which deals with improvement of cancer care in the community setting (i.e. close to where patients actually live) and the continuation of care after the initial phase of treatment. The current chapter focuses on travel distances to quality cancer care, which is of particular importance since many costs may arise in the follow-up phase (e.g. travelling expenditure) that often patients need to bear themselves.

Recent research shows clear associations between travel distance to a provider and more advanced cancer stage at diagnosis (10,11), guideline adherence, utilization of effective and novel/up-to-date procedures (12–22) and (to be interpreted with particular caution) treatment outcomes (23,24). Some studies however do not show significant results (25,26). There are clear indications that the issue of inequality in access to care particularly affects otherwise disadvantaged patients (15) and, when comparing patients that live in areas with lesser access to cancer care, those with more resources (e.g. indicated by a private health insurance status) tend to receive better care (17).

The organization of cancer services should always aim to ensure that every single patient receives the highest standards of care possible as close as possible to his or her residence. The care of cancer patients should not depend on where they live, where or to which doctor or what level of care (e.g. family doctor, office-based specialist, hospital) they initially present, how familiar they are with existing services or on their socioeconomic level.

A CCCN may achieve these aims by implementing, within its region, integration of activities of several units of primary care and hospital care that provide services to cancer patients, including palliative care and rehabilitation. Also, research conducted in CCCNs may indirectly and directly improve the care of patients. Being multicentred, a CCCN can provide also for patients with limited resources (financial, sociocultural) an access point near home and therapeutic pathways that allow for timely provision of quality services within the network. Subspecialized services can be provided in one or a small number of locations within a network in order to ensure a critical mass to develop and maintain expertise. Patient transport and continuity of care should be addressed within a CCCN. Achieving these goals is one of the indicators against which the success of CCCNs must be evaluated. The development of therapeutic pathways within the CCCN is of crucial importance to patients with rare cancers, who may find the different expertise needed for their diagnosis and/or treatment spread among the various units/centres of the CCCN.

**Recommendation 5.1**

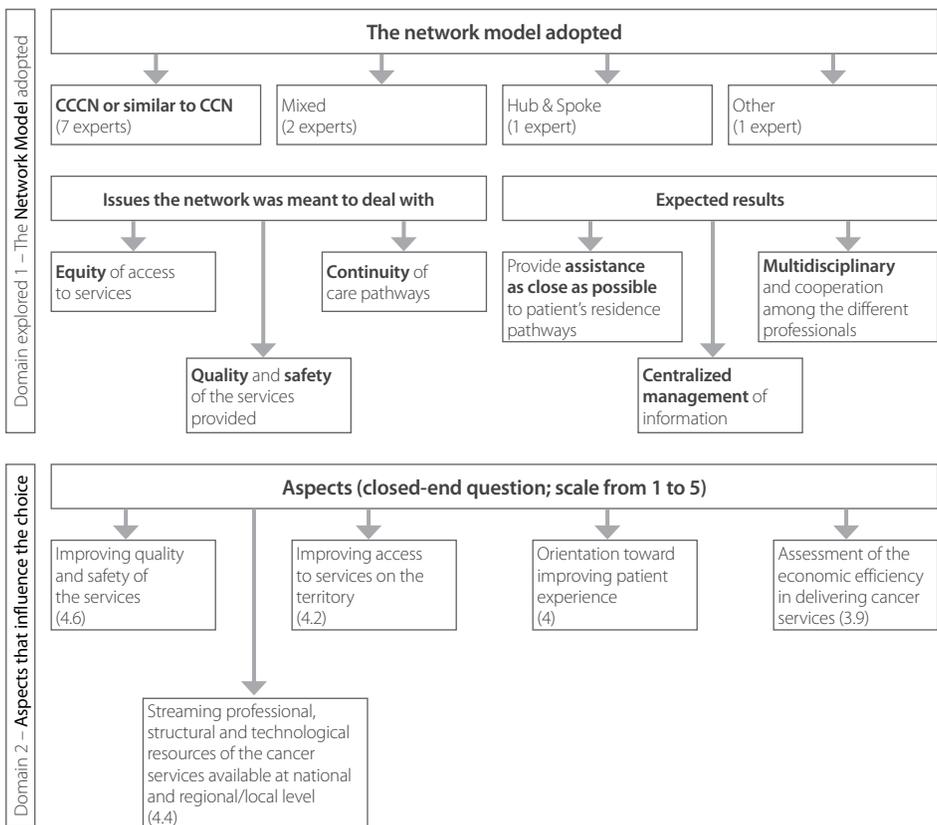
Since physical distance from quality cancer care is a major cause of inequality, it is recommended that clearly defined multiple access points are made available as close as possible to where patients reside, and that uniformly optimal care be provided as close to home as possible.

CCCNs can also be set up also for additional specific reasons depending on the regional and country contexts and the purposes a network is expected to serve.

In the United Kingdom, for example, managed clinical networks were introduced to improve the quality of care and the equality of access (across social or geographic variables), with strengthening of clinical governance, increased specialization of units and more efficient use of resources (2,27,28).

An expert consultation held in 2015–2016 with 11 experts from nine EU Member States (Bulgaria, France, Germany, Hungary, Ireland, Italy, Portugal, Spain and the United Kingdom) revealed that equality of access, quality and safety, as well as continuity of services, were considered key drivers for favouring/ setting up cancer care networks (Fig. 5.2).

**Fig. 5.2** Conceptual map showing the main results of an expert consultation with 11 experts from nine EU Member States (Bulgaria, Germany, France, Hungary, Ireland, Italy, Portugal, Spain and the United Kingdom) in 2015–2016



Among the most important functions of CCCNs is that of improving outcomes for cancer patients. Current evidence indicates that treatment outcomes for certain types of tumour are likely to be suboptimal in units where very small volumes of activity occur (29,30).

### Structure, governance and geographic context

The establishment of a CCCN in a country or region will present new challenges. Because a CCCN may comprise a number of organizations or service units across the patient pathway, it is necessary for the units of the network to work together in a uniform and cohesive manner.

An agreed governance framework is required for the operation of a CCCN that clearly defines the role of each unit/organization participating in the network, as well as for reporting the network's activities to national or regional authorities. The governance structure of the CCCN will direct all the activities associated with cancer control across the continuum of cancer care. By agreeing on the precise role of each networking unit, the location of specialized services will also be defined. All units will be responsible for setting specific standards for the development and revision of clinical guidelines.

A CCCN board should include representatives of the various stakeholders in the network, including clinicians and patients. The CCCN would also benefit from a dedicated office and executive team, including a director, to provide overall leadership and management for the operation of the network. Appropriate skill mix of staff should include senior managerial and clinical leadership with appropriate administrative support. In practice the suggested governance structure can be adapted to the needs of each network.

In terms of population size, the network will ideally cover an area allowing it to be self-sufficient for the majority of cancer care. Health services should be delivered locally where this is clinically appropriate and possible (31). It is considered that a larger-sized network provides overall patient benefits through central efficiency gains, facilitation of the introduction of service developments and new treatments, increase in the number of patients entered into clinical trials and establishment of internal benchmarking of clinical performance (32).

It is suggested that a CCCN should serve a population of one to two million people (2,33). For very rare cancers, services may have to be centralized to a national or regional centre, into which all local and regional CCCNs feed. In deciding what area should be covered, consideration must be given to geography, administrative status (e.g. regional, supraregional), population size and density for the CCCN, pre-existing cancer services, physical and capital infrastructure as well as workforce capacity. Staffing is a major contributor to both processes and outcomes and is key to the success of a network.

The number of health care professionals and the population they cover can vary widely depending on the country. However, an examination of staffing levels and mix for all oncology professionals (e.g. oncology surgeons, specialist nurses, radiation therapists and other health professionals) in line with international norms is an appropriate starting point (34–38).

There is a strong case for developing a strategic approach to future workforce needs in light of the pace of innovation in cancer care and the increasing demands of an ageing population (29). Integrating workforce planning with service and financial planning can ensure that human resource decisions are linked to the goals of the network.

**Recommendation 5.2**

We recommend that it be regarded as a priority to establish CCCNs, which are multicentric complexes that bring together units dealing with the management of all aspects of cancer care. These units will be in different locations and under a single governance structure. They will undertake to work together consistently in a structured integrated manner in order to pursue their common goal with greater effectiveness and efficiency.

**Outcome indicators, certification and quality assurance**

Based on scientific literature and on the testimony of experts regarding possible indicators to be used when planning the network, a set of input, process and outcome parameters has been identified for supporting policy-making and the decision-making process (Table 5.1).

**Table 5.1** Possible indicators and/or measures to be used when planning a network

<b>Areas of indicators</b>	<b>Indicators and/or measures referred by the experts</b>
Input	<ul style="list-style-type: none"> <li>• Consumption rates of the population in the different districts/areas of the network for the main essential levels of care: per capita cost for cancer drugs, radiation treatments per 1 000 inhabitants</li> </ul>
Process	<ul style="list-style-type: none"> <li>• Uniformity of clinical choices in specific points of the diagnostic and treatment pathway for different oncological diseases</li> <li>• Number of patients at the beginning of their care pathway/total number of people with cancer</li> <li>• Number of tumours in each area in which the hub &amp; spoke setup has been divided/general population</li> <li>• Research and scientific productivity indicators: average impact factor per researcher, ability to attract funding</li> <li>• How many patients are discussed within a tumour board</li> <li>• How many patients have psycho-oncological support</li> <li>• How many patients have social service counselling</li> <li>• Patients whose staging is completed by the expected time</li> <li>• Patients whose treatment begins as expected</li> <li>• Patients who undergo the agreed follow-up programme</li> <li>• Performance in end-of-life management (e.g. chemotherapy in the latest 14 and 30 days, change in treatment, using integrated home assistance and hospice)</li> <li>• Presence of health care workers required for the centre</li> <li>• Online dashboard</li> <li>• Communication with the GP</li> <li>• Process indicator fulfilment does not vary between patients from different social status groups</li> </ul>

Areas of indicators	Indicators and/or measures referred by the experts
Outcome	<ul style="list-style-type: none"> <li>• 30-day mortality for surgery required for the specific cancer treated</li> <li>• 90-day mortality for the same cases as above</li> <li>• New intervention within 30 days after surgery for the same cases as above and related mortality rates</li> <li>• Outcome of care in different point of the network (i.e. pain management, health care-associated infections, falls)</li> <li>• User satisfaction</li> <li>• Survival rates at 1 and 5 years</li> <li>• Outcome indicator fulfilment does not vary between patients from different social status groups</li> </ul>

However, this list can be seen as a starting point for future studies that are necessary to appropriately design a set of ad hoc indicators not only for decision-making leading to a CCCN but also to evaluate its implementation.

An important aspect of the functioning of a network is that it continually operates at the highest level of sustained quality and that its operations are of comparable quality to other networks within a country or region. Appropriate governance arrangements to maintain quality in the long term and to provide periodic evaluation to show trends in relevant performance indicators are, therefore, needed.

There are two potential approaches that have been explored internationally. The first is a “national overview panel” that formally assesses the quality of each CCCN. Such oversight is being developed for cancer centres and there are good examples across Europe. In Germany, the German Cancer Society has successfully developed oversight panels that formally assess the quality of all certified cancer centres across the country (39). The alternative is a peer-review process in which individuals from one or more cancer care networks come together to review the work of a separate network drawing on their shared experience of high quality and outlining areas for improvement from their experience, from the evidence-based literature and from national guidelines.

Measuring the performance and quality of cancer care services and programmes is essential to ensure that objectives are being met. Provision of accurate and timely information is a central requirement and this information underpins evidence-based and informed decision-making by policy-makers, researchers, health professionals and patients.

It is necessary to have information technology systems to support improvements in cancer control in the network, with clear legal and administrative frameworks for the collection, sharing and reporting of these data.

Having a unique patient identifier and electronic health record will also facilitate the optimum care of patients across the CCCN. Such data systems will also facilitate the generation of audit and review reports at the network level.

### **Recommendation 5.3**

Given the benefits that a CCCN can provide with respect to equality of access as well as quality of cancer care, it is recommended that the creation of one or more CCCNs is always considered in decision-making. When in a certain area a comprehensive cancer centre already exists, a CCCN can be built with it as its core. Performance indicators and evaluation models should be defined from the outset of the network.

## **Operation of a CCCN**

Care of cancer patients within a CCCN must encompass all phases and all aspects of the disease and aim at all patients receiving continuous, adequate treatment, care and support from appropriately skilled professionals (40). This implies that the network consists of tumour-based multidisciplinary and multiprofessional teams (41). Multiprofessional cooperation in the network contributes to better patient and caregiver satisfaction and improves decision-making and guideline adherence within the network (42–46), although methodological limitations make firm causal associations difficult to establish (47). The teams must include all experts and contact people who are required in order to cover screening as well as all stages of the disease from diagnosis and treatment (involving inpatient and outpatient units), to rehabilitation, follow-up and palliative care. A defined pathway must be put in place to ensure that patients, regardless of point of access, will be referred to a unit knowledgeable of the disease to start patient management in collaboration with the coordinating referral centre. All steps must be accompanied by psychosocial support (48,49). The use of complementary medicine should be carefully explored with the objective of managing treatment side-effects (50). Special attention must be directed to survivorship of patients, as well as the transition from childhood to adult units for young adults with cancer and the collaboration between paediatric and adult oncology professionals.

## **Tumour management groups and patient involvement**

Tumour management groups are essential to the operation of a CCCN. It is the tumour management group that must discuss a treatment plan for every patient as soon as the diagnosis is made (47), and it is the tumour management group that must periodically review individual steps along the treatment pathway. Each tumour management group must include members of all disciplines and professions required in order to deal with every aspect of the particular type of tumour covered by that group. Each member of the team must be known by name, and the tasks of each must be clearly defined. Within a CCCN, for at least the most common cancer types, uniform standard operating procedures must be in place; these will be based on tumour-specific national and European guidelines. The equipment for diagnostic imaging, for surgical procedures, for radiotherapy and any other intervention must comply with evidence-based guidelines and must be used according to existing standard operating procedures. The tumour management group is responsible for the development of the standard operating procedures and must critically review if all members of the tumour management group treat the patients according to these procedures and must analyse the quality of care within the network.

All members of a tumour management group must be qualified with appropriate national/international degrees in their respective specialties, and they must update themselves regularly through continuous education. The personal and technical requirements described above should be defined nationally on the basis of the European Guide on Quality Improvement in Comprehensive Cancer Control.

Different treatment options for a specific disease must be discussed with the patients within the context of the participatory decision-making model and patients' preferences must be taken into account while the patients and the professionals agree on a treatment plan.

## Integration

A CCCN is an integrated structure bridging different care sectors such as primary, secondary, tertiary and social care. Bringing links between primary care and cancer services is clearly critically important for timely access to the best treatment. However, integration between cancer services and non-cancer hospital services is equally important in modern practice. Comorbidity in cancer patients requires that their management be shared with specialists in other specialties such as cardiology, respiratory medicine or gastroenterology. Acute oncology in which patients may be in need of urgent or emergency treatment for the complications of their cancer or complications of cancer treatment (e.g. infection) will usually require close integration of cancer services with critical care services and acute medical and surgical services. Cancer networks cannot, therefore, be developed in separation from general health care services, and the provision of integration with a general health care service is a particular challenge for single specialty cancer hospitals, which are still an important part of cancer services throughout Europe.

## Care pathway quality indicators

In order to assess the quality of cancer care within the network, care quality indicators should be identified. Quality indicators should be simple, tumour specific and whenever possible evidence-based and uniform throughout the CCCN. With the implementation of local and national quality assurance programmes (e.g. internal and external audits), quality of care will be visible and, even more importantly, different aspects of care can be observed and compared across providers, for example diagnostics or surgery according to guidelines. Noticeable results for quality indicators could be discussed within each tumour management group and adequate measures could be defined in order to improve the quality indicator results. Quality indicators can help to implement a plan-do-check-act cycle in the clinical routine. Whenever possible, existing validated quality indicators that are feasible to measure should be used (avoiding developing new quality indicators whenever possible) (45,51–53).

## Palliative care

Even if the possibility of better treatment (including target therapies and immunotherapy) has increased life expectancy in many advanced tumours, it has not usually increased the cure rate; therefore, palliative and end-of-life care needs are very relevant for all advanced, progressive and recurrent solid tumours (54,55). Palliative care impact on symptom control and quality of life is evidence based, and more recently the early integration of palliative care in the clinical pathways for patients with advanced disease has also proved to be beneficial for improving quality of life, use of health care resources and, at times, life expectancy (56,57). Specific improvement in symptom control, firstly pain but also psychosocial and spiritual aspects of care, can be achieved by integration of palliative care in cancer care pathways (58,59). Palliative care delivery requires multidisciplinary dedicated teams and the development of networks of inpatient (hospice and acute hospital), outpatient and home-care services. Specialized palliative care services, at tertiary and general hospitals, hospices, day-hospitals and day care facilities, as well as the local community resources (GPs and home care), are needed to build an integrated palliative care network. Indicators of palliative care integration with oncology (51) are regarded as quality indicators of the clinical

pathway; for this reason tumour management groups should include palliative care specialists and palliative care education and research as an important part of the clinical network programme (60,61). Palliative care networks are often available but operate under different organization requirements (62–64); therefore, in most cases it is advisable that the CCCN should work in a structured way with the existing palliative care network.

### Rare cancers

Tumour-specific networks are especially important for rare cancers. Rarity is a major obstacle to conducting clinical trials (65) and, therefore, to developing effective treatments and clinical expertise to diagnose and treat these patients (66). Consequently, diagnosis and treatment may lie below optimal standards, particularly when care is delivered by institutions with limited expertise and/or low case volumes. The results of the RARECAREnet survey showed that centres/networks dedicated to rare cancers only exist in a few EU countries, and that centres cover only some of the 198 different rare cancers identified (67). In this context, the RARECAREnet project proposed criteria for the identification of centres of expertise for rare cancers (53). In a CCCN, a defined pathway must be put in place to ensure that patients, regardless of point of access, will be referred to a unit knowledgeable of the disease to start the patient management in collaboration with the coordinating referral centre. All this is crucial in order to achieve a timely access to appropriate diagnosis and treatment for patients with rare cancers and to support the concentration of resources and patients essential for translational research. Within a CCCN, one unit should be identified for each rare cancer that meets the requirement stated by RARECAREnet. Among the RARECAREnet-proposed indicators there is the establishment of a quality assurance system to monitoring the services provided. This will be essential to assess CCCNs also on the basis of rare cancer-specific quality indicators. However, in a CCCN, just like in any cancer institute, it is unlikely that there will be the expertise to cover every type of rare cancer. In cases where expertise is not available within the CCCN, the patient should be referred to an appropriate centre outside the CCCN.

#### **Recommendation 5.4**

We recommend that a CCCN adopts a multidisciplinary personalized approach based on tumour management groups integrating specialized hospital care with care in the community, palliative care, psychosocial support, rehabilitation and survivorship care plan.

#### **Recommendation 5.5**

Quality of care within the CCCN should be measured with quality indicators. A process for continuous quality improvement should be put in place and implemented.

#### **Recommendation 5.6**

For each type of rare cancer, we recommend identifying within a CCCN which unit if any can provide the necessary expertise. If for a certain cancer no suitable unit can be identified, the patient should be referred to an appropriate unit outside the CCCN.

### Research in CCCNs

There is a growing body of evidence that research-intensive organizations improve the outcomes for their patients as a consequence of their participation in research, and that research-active networks deliver better health care (1–4). Translational and clinical research results in evidence that

can have a positive impact on practice, skills and performance and can help to shape the quality of care provided. A CCCN should, therefore, have the capacity to design and conduct integrated cross-disciplinary research programmes and to undertake the dissemination of research results to drive improvement in cancer care.

A CCCN's closeness to its patient population offers incredible opportunities to advance translational and clinical research, as well as health service and health systems research, and to make new medical breakthroughs, with patients, researchers and care providers working together.

An optimal research organization within a CCCN gathers a critical mass of researchers to support integrated research programmes and has the capacity for successfully translating research results into clinical practice and decision-making. Critical mass equates to the ability to deliver research excellence, with impact and value, and creates further growth.

To facilitate investigator-driven studies across the CCCN, optimal research organization within a CCCN comprises a translational platform that connects patient files and data collection from each centre to facilitate complete longitudinal datasets; common quality-controlled and intercompatible processes for molecular diagnostic and/or other predictive testing; standardized procedures and common standard operating procedures for biopsy procurement and tissue analysis; shared resource facilities (e.g. biological resource, bioinformatics); and linkage to clinical and follow-up data.

All selected examples have developed what may be considered as the core components of an optimal research organization within a CCCN:

- a governance and management structure with executive and scientific committees;
- integrated flagship research programmes, with linkage to clinical practice and professional training;
- shared resource facilities (e.g. biobanks, bioinformatics); and
- dissemination towards and involvement of patient organizations.

Below are selected examples of how research is organized within CCCNs across the world.

### **France**

In France, seven "integrated cancer research sites" (SIRIC) spread across the country have currently been granted this site designation through a competitive international peer-review process to stimulate the pace of cancer research by combining medical services with multidisciplinary research teams. The SIRIC have established appropriate governance structures and developed shared resources/facilities (biobanks with linkage with clinical and genetic data, bioinformatics, etc.). They develop and drive innovative research programmes with strong translational and clinical dimensions and disseminate research outcomes to health professionals, patient organizations and the general public to improve cancer control (68–74).

### **Germany**

In Germany, the National Cancer Plan has defined a three-tier-model of cancer care that comprises organ cancer centres and oncology centres (both certified by the German Cancer Society) and comprehensive cancer centres (or oncology centres of excellence, designated and funded by Deutsche Krebshilfe (German Cancer Aid). The aim of the programme is to support interdisciplinary cancer centres of excellence to set nationwide standards for clinical cancer care and to strengthen

translational cancer research. Currently, 13 Deutsche Krebshilfe-designated centres are part of the programme and constitute the German Comprehensive Cancer Centre Network. The goal of this network is to promote innovative developments and set new standards. Elaboration of joint strategies, projects and other activities is accomplished by working groups (75,76).

### **United Kingdom**

In the United Kingdom, there are currently five cancer networks in London. The networks were established with the aim of facilitating seamless care across organizational boundaries (77). The current cancer networks consist of acute trusts, primary care trusts, voluntary sector organizations, and patient and user representatives in the network area, each represented on the network board, which directs and oversees the work of the network. Each network has developed local arrangements to respond to the demands of their population and environment. Networks are expected to link with high-quality cancer research institutions to develop clinical research programmes and enhance their abilities to translate research findings, innovation and education into improved clinical practice.

### **Italy**

In Italy, regions have achieved various degrees of integration of cancer services (78). The Region of Tuscany, in particular, has organized regional structures into a network that provides oncological services and research activities on cancer. The Istituto Toscano Tumori coordinates the network. "Core research laboratories" in Florence, Siena and Pisa have the objective of conducting innovative research to help to design specific therapeutic strategies for the most effective treatment of these pathologies. Integration of research is taking place not only through the core research laboratories but also through the entire network.

### **United States**

The UC Davis Cancer Care Network is a unique partnership among five cancer centres around northern and central California that includes formal clinical connections to local community cancer centres (which become affiliated to the network through an evaluation process) (79). The UC Davis Cancer Care Network is a specialty-care network linked with an academic health centre. It offers a unique model of care that marries patient-centred treatment with the nationally regarded academic expertise and innovation of a major research university. Comprehensive network services include access to clinical trials, virtual tumour boards, nursing and quality care.

The MD Anderson Cancer Network is a collaborative network between the MD Anderson Cancer Center and community hospitals (80). It provides expertise to members from quality assurance and specialty disease programmes to full clinical integration. Members benefit from the MD Anderson knowledge through access to best practices, leading edge technologies, patient treatment protocols, education, research and a multidisciplinary approach to patient care.

### **Australia**

In Australia, the Hunter Cancer Research Alliance is a multidisciplinary and multi-institutional alliance whose function is to provide capacity-building, funding and strategic support to cancer research across the translational research continuum (81). The Alliance purpose is to enhance collaboration, facilitate training and career development programmes, leverage funding for cancer research projects, develop and maintain essential infrastructure, disseminate research findings and support the implementation of evidence into practice. The Hunter Cancer Research Alliance organizes research efforts across two flagship programmes.

## Research clusters in a CCCN

Research clusters in a CCCN may be considered as an essential component of a national cancer strategy, for example for implementing next-generation sequencing platforms and supporting the deployment of experimental pathology platforms and bioinformatics platforms. They are instrumental in structuring new emerging fields, such as cancer immunotherapy, and their coordinated infrastructure attracts industry sponsorship and international collaboration.

Organizing research within a CCCN requires an initial financial investment specifically dedicated to establishing coordination and a management (governance) structure, as well as to help to develop the collaborative platforms and joint resource facilities that are critical to innovative and translational research. A grant-of-designation process conducted by health authorities is critical to the organizational process as it engages all stakeholders and increases shared ownership of the issue of upscaling of cancer care. To optimize CCCN potential, it is recommended that the CCCN scientific committee defines a few high-value flagship research programmes that best fit with their environment.

### **Recommendation 5.7**

We recommend that each CCCN takes full advantage of the proximity of patients, researchers and care providers to pursue basic, translational, clinical, outcome and population research programmes of high quality that will be of high value in supporting the delivery of optimal patient care within the CCCN.

## A real-life, real-time example of creating a CCCN (Czechia)

This section describes the CCCN pilot project initiated in 2015 in Czechia in close association with a newly introduced national cancer control plan. The sharply increasing prevalence of cancer in Czechia could only be managed if there was an effective infrastructure of care and a well-organized networking of health care providers to maintain reasonable potential to improve patient flow in the system and to achieve equity in access to high-quality standards of care. Therefore, the mission of the project was to optimize the care of every cancer patient in the target region. As part of the process of setting up a CCCN, potential geographical areas were explored and the South Moravia and Vysocina regions were identified as appropriate in respect of demographic and epidemiological parameters. The structure of the CCCN is representatively wide and includes general hospitals, cancer centres, research and educational facilities. One purpose of the pilot was to verify that contractual agreements among network elements, structured collaboration with common governance, a common database encapsulating a unified patient information and quality assurance system, all characteristic of a CCCN, were compatible with full respect for established institutions. Multiple access points to the network are controlled to help patients to receive timely treatment of equally high quality wherever they live. The sum total of researchers and clinicians in the pilot area are sufficient for participation in clinical trials, real world surveys and for the effective use of complementary expertise in cancer management. All methodologies used and progress being made are fully reflected in two web portals (82,83). Using these platforms, patient-outcome data of the pilot CCCN will be promptly available and usable by the cancer care system in other regions of Czechia. So far we can confirm that the CCCN model is both viable and advantageous for cancer care management.

## Background of the CCCN pilot

The CCCN pilot was established in an area covering a population of 1.6 million inhabitants (14 000 km<sup>2</sup> population density 120 inhabitants/km<sup>2</sup>). The mean age of the population was 42 years, and 17% of people were older than 65 years. In 2013, there were 13 190 patients with newly diagnosed cancer, and serial data revealed a growing trend with an annual increment of 1.8%. Cancer is the second highest cause of mortality in the region (26% of all deaths), and cancer mortality (4089 in 2013) had been stable over several years. Increasing incidence with stable mortality suggests a significant increase in prevalence; in 2013 there were 88 340 patients with cancer (a 4.3% annual increment). As for most common cancer types, the incidence figures (per 100 000 inhabitants) were as follows: prostate cancer 133, breast cancer in women 125, colorectal cancer 77, lung cancer 52 and, renal cancer 29. In 2007–2014, there were approximately 2.8 million hospital admissions, of which 9.1% were for cancer as the primary reason.

## Principles adopted for setting up the pilot CCCN

The CCCN model was developed within the Czech health care system with due regard to the following key principles, which can also be applied as policy recommendations:

- the formation of the CCCN was based on a voluntary decision of health care providers; political authorities favoured close collaboration among health care providers but there was no compulsion to take part in the CCCN;
- the CCCN was established not as parallel/alternative to other organizations in the chosen area but as the preferable global model; pre-existing cancer care facilities were never removed but, rather, were improved and, consequently, creation of the CCCN has not resulted in competition with other institutions;
- operation of the CCCN needed to be supported by new legislation so that hospitals that participated could do so legally; the legal framework also made it possible to centralize processing of clinical data: initially one of the major obstacles to be overcome;
- the CCCN was made up of not just the hospital sector but also diagnostic centres, primary care providers and palliative care units; it was facilitated by a common information system and cancer research and educational facilities were included;
- a legally binding written agreement was signed by the institutions that form the CCCN, defining its organization and governance; there is a shared system of multidisciplinary tumour management teams, common clinical protocols to which all must adhere, a common information system and a common database supporting a unified quality assurance system; and
- the objectives of the information system of the CCCN include the following: identification of inequalities in care, feedback control of effectiveness of interventions supporting equity, and population-based quantification of outcomes using uniform performance indicators.

## Decision-making process in the creation of CCCN pilot

The CCCN is in harmony with the national health care organization and reimbursement mechanisms. First, core members of the CCCN were certified by the Czech Ministry of Health as cancer centres. Second, based on a feasibility study, regional political authorities invited cancer care providers to become part of a CCCN. These two steps, certification and statement of political will, have been crucial for placing the CCCN on a solid foundation, pre-empting fragmentation

of resources among different providers. Third, ad hoc legislation was passed in order to make it possible for a network (such as a CCCN) to be incorporated into the system as a reimbursement recipient. Fourth, the centralized processing of data from individual institutions required legal authorization. Finally, collaboration with high-volume university hospitals was optimized in order to provide the CCCN with an effective educational backbone.

### CCCN pilot: structure

The CCCN incorporates one comprehensive cancer centre of high national repute (Masaryk Memorial Cancer Institute; [www.mou.cz](http://www.mou.cz)), three specialized cancer centres and four general hospitals. For the creation of a CCCN, the inclusion of the Masaryk Memorial Cancer Institute, which has all the features of a high-volume comprehensive cancer centre, has obviously been a major asset. Together with the Jihlava Cancer Centre ([www.nemji.cz](http://www.nemji.cz)), dominant in the Vysocina region, and two university hospitals ([www.fnbrno.cz](http://www.fnbrno.cz); [www.fnusa.cz](http://www.fnusa.cz)), these four institutions have been the core of the newly formed CCCN: they took responsibility for establishing binding cancer care protocols, as well as for the rules for the operation of multiprofessional teams and quality assessment standards. Collaboration with the four general hospitals enabled the CCCN to redistribute services with the aim of providing care as close as possible to a patient's residence. Most of the more common cancers are treated locally in any one of the eight institutions; whereas services for haematological malignancies, childhood cancers and other rare cancers are centred at university hospitals in Brno city. The CCCN is also closely associated with medical schools (Masaryk University, Medical Faculty, Brno City; [www.med.muni.cz](http://www.med.muni.cz)), cancer research teams, tissue banks and bioinformatics facilities.

### CCCN pilot: monitoring outcomes

The CCCN pilot is supported by two key interactive web portals:

- a national portal ([www.onconet.cz](http://www.onconet.cz)) centred on cancer care management that maps infrastructures and facilitates navigation for both public and professionals; and
- a web portal ([www.cccn.onconet.cz](http://www.cccn.onconet.cz)) that outlines and details the structure of the CCCN and the rules according to which it operates; it includes methodologies, charts of patient pathways and data standards for outcome measures.

The portals have the dual purpose of providing information to patients and the public and facilitating communication among professionals and dissemination of the CCCN experience. As measures of success of this CCCN, we have identified the following end-points: improved equity of standardized care, improved continuity of cancer care pathways and adherence to shared protocols.

The portals reflect the progress of the CCCN with respect to these parameters and they focus on five crucial distinguishing features, all of them relevant to the national system of cancer care management.

- **Complexity of CCCN activities.** The portal mapping infrastructure (82) will cover all aspects of comprehensive cancer care in the area of interest.
- **Impact of the CCCN over the entire extent of its catchment area.** The portal ([www.onconet.cz](http://www.onconet.cz)) will list and show graphically all services accessible within an acceptable distance from a patient's residence. Online tools will provide real-time information on timetables and so on.
- **Multilevel information system.** This is implemented at each one of the CCCN component institutions. A full guide is available at the CanCon web site for Czechia (83).

- **Common governance.** The modalities and rules are detailed on [www.cccn.onconet.cz](http://www.cccn.onconet.cz) in four layers: management rules, multidisciplinary tumour teams, cancer management protocols and e-learning/e-communication links.
- **Common database reporting.** This database enables professionals to monitor how patients progress along their management pathways. Equity in access and benchmarking of performance indicators are also monitored, and burden predictions periodically updated. The CanCon web site (83) combines interactive data views and compiled e-reports.

## Discussion

Cancer networks are an innovative and efficient manner to streamline patient pathways at the regional, national and EU level because they facilitate multidisciplinary cancer care as well as prompt access to reliable diagnosis and specialized management of the complexity of the cancer care pathway. One of the main challenges for the network approach is to balance organizational innovation against stability. In other words, it is essential to assess to what extent existing cancer care facilities fulfil the needs of the population of a certain region, with special attention to providing equality of access as well as quality of cancer care; where deficiencies are identified, these may warrant the innovative effort of establishing a CCCN.

The main potential advantages making the case for CCCNs are listed below.

- A well-integrated CCCN is more likely to achieve equity in access to good-quality care nearer home; indeed, studies have found that distance is a significant factor in not being able to attend a comprehensive cancer centre.
- A CCCN implements a patient-centred approach thanks to common principles, attitudes and management protocols agreed among professionals.
- A CCCN will be able to acquire resources that an individual hospital may not and allocate them more efficiently across the network; it will be able to avoid unnecessary duplication of facilities; and facilities that are underutilized in a particular site can be put to better use once a CCCN is in operation. All these factors will improve cost-effectiveness.
- A CCCN can capitalize on complementary expertise of individual professionals for both short-term and long-term planning.
- A CCCN can provide a seamless care pathway, even for patients requiring unique or complex treatment procedures that need moving the patient to more than one place as part of the management pathway.
- A CCCN, through the units of which it consists, will be closer to primary care or even fully integrated with it and, therefore, in a good position to liaise with it.
- A CCCN gathers optimal conditions to conduct not only basic research but also translational research, observational studies, clinical research and health services research; this is made possible by having a critical mass of researchers and clinicians, a common patient information platform, standard operating procedures for tissue analysis, and shared biological resources and bioinformatics facilities.

## Conclusions

Many types of cancer network exist in Europe: some just on paper, others in reality. Here we have outlined in some detail a very specific type of network, the CCCN, characterized by a deliberate and comprehensive integration of activities, as defined at the start of this chapter. A CCCN is a highly integrated multicentre structure that works under a single governance and deals with the management of all aspects of cancer care. When planning a CCCN, several indicators must be taken into account so that the CCCN is optimally tailored to local needs in terms of cancer epidemiology and pre-existing cancer care facilities. An essential characteristic of a CCCN is the establishment and operation of a multidisciplinary personalized approach based on tumour management groups encompassing specialized hospital and community care, including palliative care, psychosocial support, rehabilitation and survivor care planning. Consequently, a CCCN can become a superior instrument for meeting the challenge of the increasing needs of the increasing numbers of cancer patients, providing equity, quality and cost-effective cancer care. A CCCN will adhere to existing guidelines with regard to the management of rare cancers. An articulate quality control programme must operate in a CCCN from the outset in order to pursue, maintain and improve the way its objectives are achieved. In addition to the provision of cancer care, a CCCN will be ideally poised to conduct not just basic research but also translational projects, clinical trials and population-based research programmes. Of course, further studies will be needed to better quantify improvements in actual cancer care brought about by a well-structured CCCN in terms of patient general outcome, equity and cost-effectiveness. In the meantime, it is encouraging that within the time frame of the CanCon Joint Action a CCCN as here defined has been set up and is now in operation in the south of Czechia.

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# EU policy recommendations for quality improvement in cancer after-care at the community level

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## Introduction

What is cancer after-care? Cancer after-care is the period when care is provided to patients who are in remission and have completed the planned disease-specific oncological care. They are monitored for recurrence and late effects of treatment but can be generally classified as cured. The modalities of organization of this care differ largely across countries and may be through arrangements in hospitals and their outpatient departments, through community care providers or in a combination of the two.

One of the important positive effects and challenges associated with recent advances in cancer treatment has been the constant rise in the number of cancer survivors. These might be patients who are in long remission periods as well as patients who are receiving life-prolonging treatments. Increasing incidence and prevalence of cancers, through the ageing population and the increase in some risk factors (e.g. obesity, physical inactivity) is leading to an increasing demand for oncological care closer to home. Consequently, the importance of coordinating processes and patient pathways in cancer care across levels of care has been increasing. Grunfeld and Earle stressed the importance of “transitions”: from focus on diagnosis and treatment to long-term follow-up care, management of late effects, rehabilitation and health promotion (1). Throughout these transitions, collaboration between oncologists and GPs is crucial. This collaboration can be challenged by variable interest, poor communication with GPs and patient preferences for follow-up (2). The last issue also relates to differences in health systems and organizational preferences arising from a specific health care system (e.g. strong stress on hospital and specialist care, free access to specialist, low profile for PCPs).

After-care was traditionally in the hands of cancer centres and hospitals treating cancers. Increasing incidences, ageing of populations, increased complexity of the initial phases of cancer care and changing patterns of care at the community level now pose a challenge and the need to place an important share of cancer after-care in the hands of PCPs. One of the challenges arises from the

costs of oncological care within cancer centres or specialized hospital departments. In addition, intensification of oncological care, particularly at the level of medical/clinical oncology, has meant focusing time and efforts on patients receiving treatment, to the detriment of the after-care phase. A further consequence is that after-care is less well defined and, most importantly, less structured. Cancer patients also face social challenges – loss of work capacity, rehabilitation, disability and/or mental problems – which all require a comprehensive psychosocial approach close to a patient's living and working environment. In view of these challenges, structured development of (new) pathways should ideally encompass the transfer of cancer after-care into community care settings along with adequate training of all health and social care professionals involved in the process. Proper reallocation of tasks is necessary in order to secure an adequate quality of care, its continuity and a seamless process, as well as for maintaining a high level of patient trust and cooperation. In addition, most cancer patients are older and very often have chronic diseases before their cancer diagnosis, particularly cardiovascular diseases, diabetes or a neurological problem. Cancer survivors have different types of need that may be insufficiently met by general practice (3).

Two further terms need explanation and clarification with respect to the context in which they are used throughout this chapter – primary care and community care. It was decided to use the term community care as it encompasses the wider range of services necessary for any patient with a chronic condition. These services go beyond the immediate care delivered within health care and are specific in cancer patients because of the range of outcomes, including long remissions and cure. Community care also needs to address social, economic, employment, financial and spiritual needs of patients, which arise either from the longitudinal nature of the disease or from the consequences of the treatment and their impact of the patient's daily life, economic, employment, social life and other activities. Care of patients at the community care level will be explored as a challenge in changing health systems where rational approaches should ideally meet with patient preferences.

This chapter focuses on the organization of after-care and supportive care for patients, predominantly outside of specialized oncological care. The latter normally encompasses the specialized and focused curative treatment that is prescribed based on a baseline assessment of the patient's disease. Once in remission and classified as without active disease, patients mostly return to their lives before cancer. Nevertheless, this phase and period pose different challenges, both for the patient and for health care services at the community care level. Chapter 7 will focus on patient experiences and will deal with the first group of challenges through an analysis of the current state in this field as well and by proposing a survivorship care plan. Here we explore the organizational and process aspects of the organization of cancer after-care for those patients who require further interactions with community and social care because of their cancer treatment. The chapter does not generally include patients requiring palliative and end-of-life care apart from the case study of Norway, where care for this group of patients is inseparably connected to the organization of after-care. The organizational framework provided by the health system is also one of the important levers to secure equitable access to necessary services, attempting to avoid any increase in differences among patients based on social, geographical, gender or other characteristics. The ambition here is to draw attention to this specific segment of cancer care in order to:

- define after-care for cancer patients better, including the different services (as required by patients and their needs) and the organization of community care for these patients, their spouses or significant others, carers and families;

- outline how after-care is organized in certain European countries and highlight positive experiences; and
- argue for the need to structure and carefully plan the *entire* span of the cancer patient pathway including after-care, with full support in terms of adequate resources.

The chapter presents an inventory of what information on after-care is available for GPs as their role expands and an overview of national and regional practices on how the phase of cancer after-care is organized in Bulgaria, Denmark, the Netherlands, Norway and Slovenia. Four of these countries have a GP gate-keeping system and a strong role of community care, including in the cancer after-care process. Only in Bulgaria does after-care remain the task of cancer hospitals. Based on these findings, we will draw tentative conclusions, which will translate into draft policy recommendations for the future development of patient pathways for cancer after-care and its management in community care settings.

## Methods

This chapter describes the analyses done within CanCon and incorporating findings of previous, current and ongoing research. Five European countries – Bulgaria, Denmark, the Netherlands, Norway, and Slovenia – were actively involved in its development by virtue of their participation in the project. The countries presented in this chapter were included given the interest of their respective ministries of health in participating in the project. This is, therefore, self-inclusion and not a systematic and structured involvement of specific countries. Following the self-inclusion, the methodologies used in the different countries in order to substantiate some specificities of their after-care process, the relationship between levels of care and the relationship between central and regional activities vary greatly. Consequently, there was no overall harmonization of methodologies.

A short description of the methods is provided here, while a detailed description can be found online (supplemental information provided at [www.cancercontrol.eu](http://www.cancercontrol.eu)).

Given the diversity of country cases and the respective foci of their research, a series of methods were used for data collection:

### Survey of experts and country informants

A survey of experts and country informant was carried out with the collaboration of national contact points: project partners, ministries of health, cancer centres and public health institutes and similar services. Experts from all EU Member States, Norway, Switzerland, Iceland and Turkey participated in identifying guidelines as well as providing national or regional guidelines that included relevant information for GPs.<sup>2</sup> Experts from 12 countries (Czechia, Estonia, Greece, Iceland, Latvia, Luxembourg, Malta, Slovenia, Slovakia, Sweden and Turkey) indicated that there were no tumour-specific guidelines containing information on after-care relevant to GPs. The remaining

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<sup>2</sup> Delegates from national primary care associations, nurse associations, universities with a medical department, the Cancer and Primary Care Research International Network, the European Forum for Primary Care, the European Society of General Practice/Family Medicine and CanCon collaborating and associated partners. Forty-five experts corresponding to all 32 approached countries provided filled-in questionnaires (supplemental information provided at [www.cancercontrol.eu](http://www.cancercontrol.eu)).

experts indicated that there was at least one tumour-specific guideline. Despite multiple efforts, eight experts from seven different countries, who had indicated that their country had tumour-specific guidelines, did not provide any guideline. In total, 77 guidelines were received and 47 were deemed relevant. In databases and on web sites, 48 additional relevant guidelines were found. Literature review of existing guidelines on after-care for breast, colorectal, lung, melanoma and prostate cancer survivors focused on the relevance of guidelines for GPs. International guidelines were collected via searches on the Internet and in literature to create a more complete overview of guidelines. Databases Embase and Medline, the National Guideline Clearinghouse (4) and the Guidelines International Network (5) were searched using the terms "guideline", "breast cancer", "colorectal cancer", "colon cancer", "rectum cancer", "melanoma", "lung cancer", "prostate cancer". In addition, cancer agency web sites were accessed for relevant tumour-specific guidelines.

A category and topic list per tumour type was composed after assessing all guidance on after-care. The objective was to establish uniform categories and topics for the various tumour types. Several categories for the purpose of this study were defined: recurrence detection, long-term effects and recurrence prevention. The category and topic list can be found online (supplemental information provided at [www.cancercontrol.eu](http://www.cancercontrol.eu)). An important element was awareness, which means awareness of patients to potential recurrence, monitoring of disease development and of signs and symptoms of the disease. Guidance considered relevant was summarized into topics independently by two researchers. If guidance did not fit into the created topics or if topics became too broad, a new topic was created by discussion. Disagreements arising from decisions on scoring were resolved by discussion with a third researcher.

## **Exploration of cancer after-care organization and services in five European countries**

In Bulgaria, the National Centre for Public Health Analyses carried out a set of structured interviews on perceptions of after-care services, in particular from the point view of the type of provider. The questionnaire was based on the one developed in the first phase of the Slovene study and was focusing on the description of the provision of cancer after-care in Bulgaria, with the volumes of care and staffing in each cancer centre; no information was collected on the actual contents of care.

For Denmark, a reform of after-care is in progress. Plans on follow-up care for each main type of cancer are under preparation. These plans should address several topics regarding cancer after-care.

For the Netherlands, NIVEL carried out a series of health services research studies (see the country study report below) and measured the impact on after-care on the volume of care in a GP practice (i.e. the perspective of the service delivery). They specifically analysed these impacts from the provider perspective, measuring the increased workload, effect on carers and on other personnel delivering community care.

The Norwegian case constitutes a health services intervention study where the activities of an ongoing transformation (the transfer of certain specialist services including palliative care to the community level) are described.

The Slovene study combined a quantitative cross-sectional survey of a stratified random sample of 250 GPs practising in Slovenia, with semi-structured interviews conducted on a purposive sample of six physicians from the Upper Carniola region. GPs were interviewed about some characteristics of cancer patients on their lists and after-care delivered to these patients. One focus of this study was the exploration of links between different services in community care and social services. Finally, good practice recommendations on after-care in GP practices were developed and tested during the study.

The selection of countries included was not intended to be representative of all EU Member States nor exhaustive. It has to be kept in mind that the exploration was not primarily research oriented, but rather seeking for good practices in the countries that participated in the CanCon project.

## Results

### After-care for cancer survivors: recommendations for GPs in cancer guideline

Given the growing number of cancer survivors worldwide, there are increasing calls for greater involvement of PCPs in after-care. Currently, there is only little structured information for GPs on the best way to provide after-care. Guidelines are an important source of information on after-care for GPs. Consequently, an investigation examined what information on after-care was available and (potentially) relevant for GPs in national and regional guidelines from European countries and non-European western countries (Box 6.1). An inventory of tumour-specific guidelines on the five most common tumour types (breast cancer, colorectal cancer, lung cancer, melanoma and prostate cancer) was completed because it seemed likely that GPs see those survivors most frequently, and this would create an overview of all presented guidance and advice. Other tumour-specific guidelines were reviewed to uncover additional information.

Many guidelines did not specify their target audience and so it was necessary to distinguish whether guidance was relevant for GPs. We chose to use the Dutch GP as a reference for what guidance was relevant; diagnostic tests and actions that Dutch GPs could perform were identified as potentially relevant. This included all actions that could be performed within the general practice, as well as tests that could be requested from a laboratory (blood tests) and routine screening tests where results are routinely sent to the GP (e.g. mammography). Expensive invasive diagnostic tests that hospitals normally provide (e.g. magnetic resonance imaging) were identified as irrelevant for GPs. The same applies for treatment of recurrence normally provided in secondary care.

In total, information on 95 guidelines (47 obtained via experts and 48 identified via literature and Internet searches) originating from 36 countries was extracted and summarized into topics (Table 6.1) (supplemental information provided at [www.cancercontrol.eu](http://www.cancercontrol.eu), including a list of included guidelines and the providing countries).

**Table 6.1** Number of guidelines and their focus concerning after-care guidelines and providers

<b>Cancer location</b>	<b>Number of guidelines</b>	<b>Countries with guidelines</b>	<b>No. guidelines focusing on after-care</b>	<b>No. of guidelines with at least one scientific reference to after-care</b>	<b>Guide for GPs</b>
Breast	24	19	7	17	4
Colorectal cancer	21	16	6	12	1
Lung	17	11	3	9	1
Melanoma	15	13	1	12	1
Prostate	18	14	4	14	1

### Breast cancer

All of the 24 guidelines related to breast cancer recommended performing physical diagnostic tests (history and physical examination) and diagnostic imaging (mammography) but showed less consensus about the frequency. All guidelines agreed on an annual examination after five years, which reflects that most recurrences happen within five years of treatment (6). Five of the 20 recommended time intervals were evidence based. These recommendations showed nearly the same inequality in consecutive time intervals; there was only more agreement on the intervals in the first two years after diagnostic tests (every three to six months). More agreement was observed on the frequency of mammography. Nineteen guidelines recommend performing a mammogram annually (supplemental information provided at [www.cancercontrol.eu](http://www.cancercontrol.eu)). Most of the guidelines recommend check-ups every three to six months in the first three years after treatment, followed mostly by six-monthly check-ups until after the fifth year.

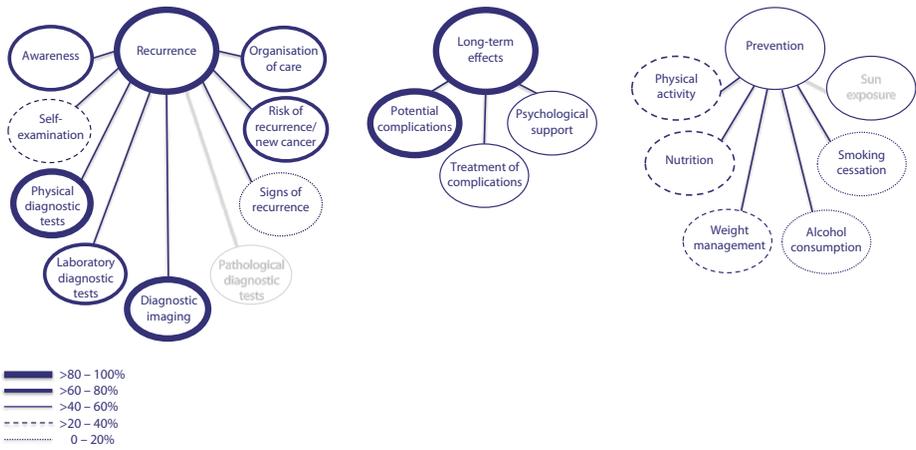
The breakdown of the different tests and procedures related to breast cancer after-care is presented in Fig. 6.1, including the weight given to the different tests. Tables 6.1 and 6.2 present the frequency of the key elements of the guidelines per number of the guidelines in which they had been identified (see above). Laboratory diagnostic tests were considered as non-routine tests. Only seven guidelines provided recommendations on self-examination by the patient.

**Table 6.2** Number of guidelines on breast cancer by after-care category and number of topics dealt with per category

<b>After-care category</b>	<b>Topics dealt with</b>
Recurrence detection (24)	Physical diagnostic tests (24)
	Diagnostic imaging (24)
	Awareness (15)
	Laboratory diagnostic tests (19)
	Risk of recurrence/new cancer (4)
	Organization of care (16)
	Self-examination (7)
	Signs of recurrence (4)
Long-term effects (22)	Potential complications (20)
	Treatment of complications (11)
	Psychological support (14)
Recurrence prevention (10)	Physical activity (9)
	Nutrition (5)
	Weight management (8)
	Alcohol consumption (3)
	Smoking cessation (2)

**Note:** Total number of guidelines on breast cancer: 24.

**Fig. 6.1** Overview of categories and topics on after-care for breast cancer derived from 24 guidelines

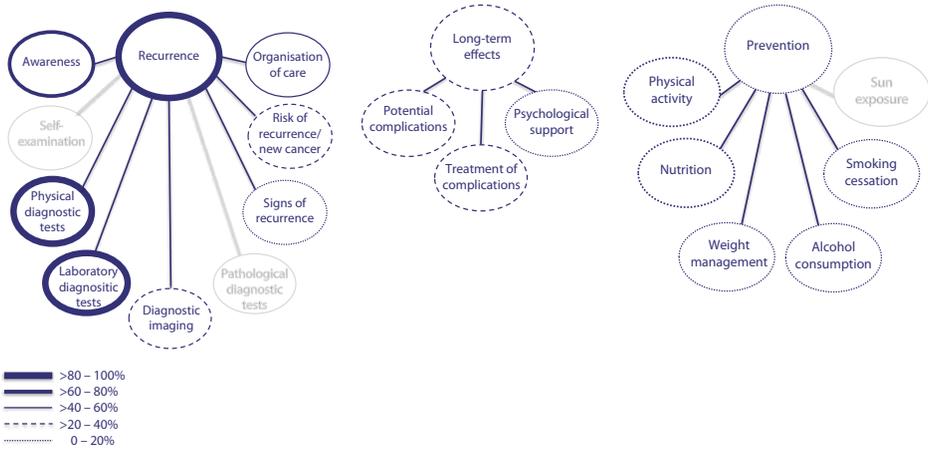


**Note:** Topics shown in grey were not discussed in the guidelines.

## Colorectal cancer

Two guidelines were specific for colon cancer and two for rectal cancer. In total, information from 20 guidelines was used. Fig. 6.2 presents an overview of the potentially relevant categories and topics for GPs. All 20 guidelines provided information and recommendations on recurrence detection; seven topics in this category were identified. Laboratory diagnostic tests (carcinoembryonic antigen testing), physical diagnostic tests (history and physical examination), awareness and organization of care received most attention. One of the six after-care-specific guidelines discussed long-term effects such as depression/distress, fatigue and incontinence problems. Four guidelines discussed prevention of colorectal cancer recurrence and one guideline provided information on all five topics identified within prevention of colorectal cancer (Table 6.3). Guidelines agreed on the usefulness of laboratory and physical diagnostic tests, but not on the time interval between consecutive tests (supplemental information provided at [www.cancercontrol.eu](http://www.cancercontrol.eu)). The majority of recurrences occur within the first three years (7). There was high agreement to stop diagnostic tests after five years, except in one guideline. After five years, the risk of colorectal recurrence is very low; just less than 1% of all recurrences occur later than five years after surgery (8). Only three guidelines reported that the recommendation on physical diagnostic tests was evidence based. For carcinoembryonic antigen testing, the same tendency towards less frequent tests after three years was observed, while all guidelines agreeing to stop after five years.

**Fig. 6.2** Overview of categories and topics on after-care for colorectal cancer derived from 20 guidelines



**Note:** Topics shown in grey were not discussed in the guidelines.

**Table 6.3** Number of guidelines on colorectal cancer by after-care category and number of topics dealt with per category

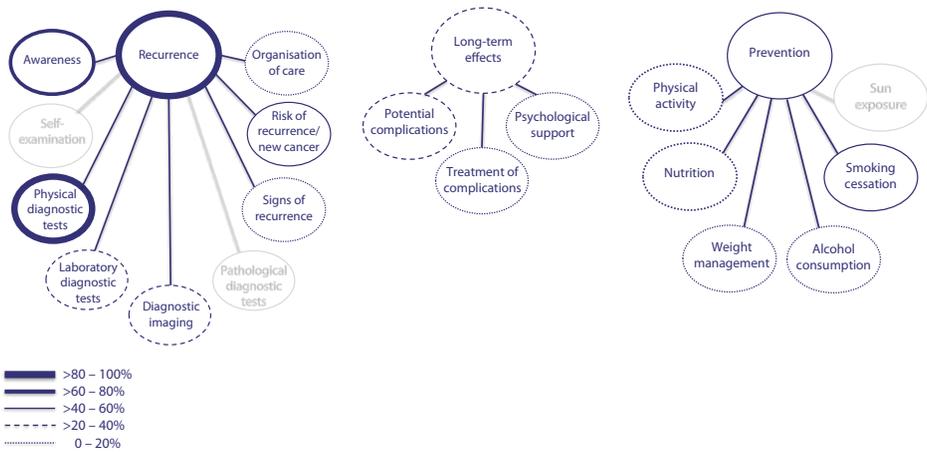
After-care category	Topics dealt with
Recurrence detection (20)	Physical diagnostic tests (18)
	Diagnostic imaging (5)
	Awareness (16)
	Laboratory diagnostic tests (19)
	Risk of recurrence/new cancer (8)
	Organization of care (10)
	Signs of recurrence (3)
	Pathological diagnostic tests (3)
Long-term effects (8)	Potential complications (8)
	Treatment of complications (5)
	Psychological support (4)
Recurrence prevention (4)	Physical activity (4)
	Nutrition (3)
	Weight management (3)
	Alcohol consumption (2)
	Smoking cessation (2)

**Note:** Total number of guidelines on colorectal cancer: 20.

## Lung cancer

In total, 17 guidelines were used to create an overview. Eight out of 15 guidelines were on both small and non-small cell lung cancer, five were only on small cell lung cancer and two were on non-small lung cancer. Fig. 6.3 shows an overview of potentially relevant categories and topics for GPs on lung cancer, identified as present in the 15 guidelines with 15 topics. All guidelines discussed recurrence detection of lung cancer, giving information on seven topics among which physical diagnostic tests and awareness were most prominent (Table 6.4). Four guidelines discussed long-term effects of lung cancer (none of them after-care specific guidelines). The most reported potential complications were pain and loss of lung function, but only one guideline provided information on treatment of complications.

**Fig. 6.3** Overview of categories and topics on after-care for lung cancer derived from 15 guidelines



**Note:** Topics shown in grey were not discussed in the guidelines.

**Table 6.4** Number of guidelines on lung cancer by after-care category and number of topics dealt with per category

After-care category	Topics dealt with
Recurrence detection (15)	Physical diagnostic tests (14)
	Diagnostic imaging (6)
	Awareness (11)
	Laboratory diagnostic tests (4)
	Risk of recurrence/new cancer (8)
	Organization of care (3)
	Signs of recurrence (1)
Long-term effects (4)	Potential complications (4)
	Treatment of complications (1)
	Psychological support (2)

After-care category	Topics dealt with
Recurrence prevention (9)	Physical activity (2)
	Nutrition (2)
	Weight management (2)
	Alcohol consumption (2)
	Smoking cessation (9)

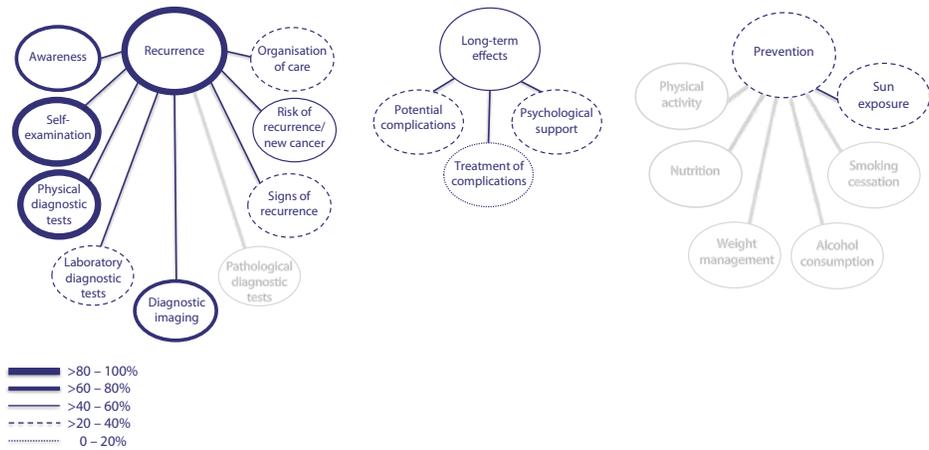
**Note:** Total number of guidelines on lung cancer: 15.

The recommended frequency was highest in the first year after treatment, corresponding to risk of lung cancer recurrence that peaks around nine months after treatment (9). Around 60–70% of the relapses occurred in the initial two to three years after treatment, reflected by the high frequency of follow-up during these years. In the fourth and fifth year, the risk of recurrence declines and recommended frequencies were once to twice a year. After five years, most guidelines recommended annually diagnostic tests or to stop testing as the majority of relapses occurred in the first five years after treatment. The two guidelines that reported that the recommendation on physical diagnostic tests was evidence based did not agree on time intervals between diagnostic tests. One recommended physical examination every three to six months for three years and then annually, while the other recommended performing physical examination every three months in the first two years, every six months in year three to five and then annually. This means that a uniform position is needed from oncologists in order to inform the PCP.

## Melanoma

All guidelines included recommendations on recurrence detection (Fig. 6.4). Of the eight topics identified, physical diagnostic tests, self-examination, risk of recurrence and laboratory diagnostic tests received most attention (Table 6.5). Melanoma stands out among the five cancer types in that self-examination is recommended as a method of recurrence detection. Eight guidelines discussed long-term effects of melanoma, focusing in particular on psychological support but also on potential treatment complications such as lymphoedema, fatigue, fear, depression/distress and thrombocytopenia. Only sun exposure was identified within the category recurrence prevention. Six guidelines highlighted the avoidance of sunburn by reducing sun exposure and tanning use. All guidelines recommended physical diagnostic tests and 12 gave recommendations on time intervals. In eight of these, the recommended frequency depended on the stage of the primary melanoma, while four gave recommendations independent of the initial stage. As the risk of recurrence is related to the primary tumour thickness (10), the frequency of follow-up depends on the stage of the primary melanoma. There is no agreement on the time intervals between consecutive physical diagnostic tests. After 10 years, seven guidelines recommended stopping diagnostic tests, seven to continue testing and two to continue if diagnostic tests were clinically indicated. Four guidelines indicated that the recommended time intervals were evidence based. There is somewhat more agreement on the time intervals if the initial stage of the melanoma was stage II or III. Time intervals are shorter compared with stage I because the risk of recurrence is higher (11). Most guidelines agreed on three to six month time intervals in the first three years after treatment. This is in accordance with the risk of recurrence, which is highest in the first two to three years after treatment (12).

**Fig. 6.4** Overview of categories and topics on after-care for melanoma derived from 15 guidelines



**Note:** Topics shown in grey were not discussed in the guidelines.

**Table 6.5** Number of guidelines on melanoma by after-care category and number of topics dealt with per category

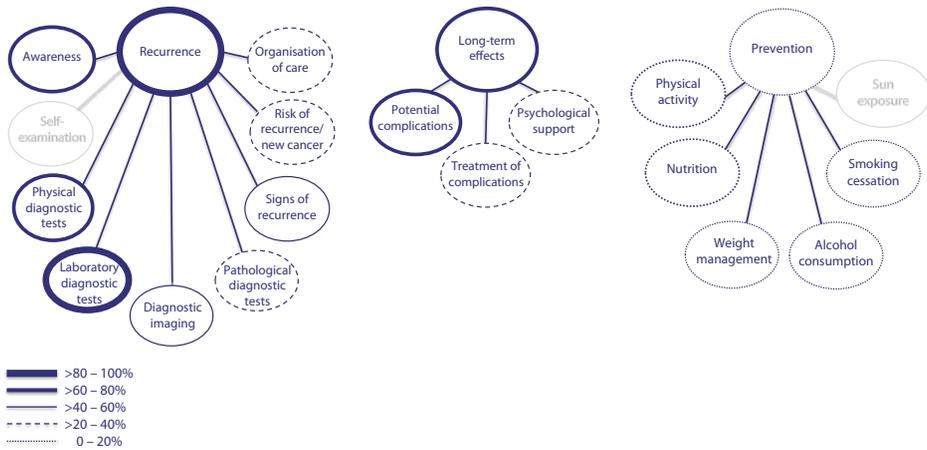
After-care category	Topics dealt with
Recurrence detection (15)	Physical diagnostic tests (15)
	Diagnostic imaging (11)
	Awareness (12)
	Laboratory diagnostic tests (6)
	Risk of recurrence/new cancer (5)
	Organization of care (6)
	Signs of recurrence (11)
	Self-examination (13)
Long-term effects (8)	Potential complications (4)
	Treatment of complications (2)
	Psychological support (7)
Recurrence prevention (6)	Sun exposure (6)

**Note:** Total number of guidelines on melanoma: 15.

### Prostate cancer

Recurrence detection was discussed in all guidelines (Fig. 6.5 and Table 6.6). Most attention was paid to the value of testing for PSA, followed by digital rectal examination and awareness; other topics were less well covered. More than half of the guidelines (11 of 18) discussed long-term effects of prostate cancer, where 11 guidelines mentioned at least one potential complication. Distinction was made between urinary, sexual, bowel and other complications; urinary incontinence and erectile dysfunction were most often mentioned.

**Fig. 6.5** Overview of categories and topics on after-care for prostate cancer derived from 18 guidelines



**Note:** Topics shown in grey were not discussed in the guidelines.

**Table 6.6** Number of guidelines for prostate cancer by after-care category and number of topics dealt with per category

After-care category	Topics dealt with
Recurrence detection (18)	Physical diagnostic tests (14)
	Diagnostic imaging (8)
	Awareness (13)
	Laboratory diagnostic tests (18)
	Risk of recurrence/new cancer (5)
	Organization of care (7)
	Signs of recurrence (10)
	Pathological diagnostic tests (5)
	Long-term effects (11)
Treatment of complications (7)	
Psychological support (4)	
Recurrence prevention (2)	Physical activity (2)
	Nutrition (2)
	Weight management (1)
	Alcohol consumption (1)
	Smoking cessation (2)

**Note:** Total number of guidelines on prostate cancer: 18.

There was not a high level of agreement across guidelines on the frequency of the two most important follow-up monitoring methods: digital rectal examination and PSA testing. The suggested frequency for digital rectal examination was either every six or every 12 months for the first three years after treatment. From the fourth year onwards, the predominant suggestion was for an annual check. There was no agreement on the frequency in the first years for PSA testing; for the second and third year guidelines leaned towards six-monthly checks. In the fourth and fifth year, there was again no agreement, while after five years it was recommended as an annual check.

## Summary

All guidelines noticed that the detection of recurrence is the most important part of after-care. Although it is known which diagnostic tests are best to detect recurrence, the best frequency to perform diagnostic tests to detect cancer recurrence is not known. Compared with recurrence detection, long-term effects of cancer got less attention in the guidelines. Most breast cancer guidelines (83.3%) and more than half of the prostate cancer guidelines (61.1%) reported potential complications of the specific cancer. Guidelines on colorectal cancer, lung cancer and melanoma provided only little information on long-term effects. Prevention of cancer recurrence received by far the least attention in the guidelines and it seems that prevention recommendations are not tumour or even cancer specific. This study does not provide the best practice on after-care for GPs, but it shows the most complete practice and an overview of information on after-care (potentially) relevant for GPs.

## Explorative studies of after-care for cancer patients in five European countries

This section presents five case examples (selection as outlined in the Methods) describing different regional and national approaches to after-care:

- Slovenia: exploration of after-care with their GPs for cancer patients in remission;
- Norway: a standardized, comprehensive patient pathway for cancer patients treated with a non-curative intent but within a clear framework of the cancer strategy;
- the Netherlands: nesting of after-care for cancer patients with GPs and primary care settings;
- Denmark: organization of after-care for cancer patients; and
- Bulgaria: organization of after-care through a network of regional comprehensive cancer centres.

The country information collected serves to give an overview, if limited, of how cancer after-care is organized in European countries and identifies potential advantages and drawbacks of different approaches. This insight will feed into the policy recommendations on how to improve cancer after-care in the future (outlined at the end of this chapter).

### The case of Slovenia: experience of GPs with cancer patient after-care

In Slovenia the transition of after-care from the hospital and specialized oncological centres to primary care is still beginning. It was decided to carry out a study that would qualitatively estimate the GPs' workload with recent cancer patients and then carry out a tentative implementation of a cancer patient pathway for after-care in GP practices/community care. So far, there had been little

information about this issue. The objectives of the study were to describe the existing practices with recent cancer patients in after-care, regardless of their current condition and disease stage; assess the relationships between GPs, other PCPs, social services and families in managing patients with cancer; and provide inputs for a better structuring of the cancer patient pathway in after-care and testing this in a certain number of GP practices.

### ***Survey findings on GPs and GP practice characteristics***

Questionnaires were completed in May and June 2015 by 32 GPs (12.8 % response rate): 27 responding GPs were female (84.4%) and the average age of responding GPs was 51.5 years (standard deviation (SD), 7.8). Data on 160 cancer patients and their treatment were collected via their GPs. More than half (18; 56.3%) of the GP offices were located in a rural area and four (12.5%) were located in nursing homes. The majority of collaborating physicians (23; 71.9%) were employed in a public primary health centre. The community care centre was on the same location as the GPs' office in two thirds of the cases (21; 65.6%).

A single GP had an average of 8501.8 (SD, 3912.5) patient contacts in year 2014, of which 55.6 (SD, 51.5) were house calls. The average number of patients per GP was 1687.8 (SD, 676.2). From those, 99.1 (SD, 95.7) were cancer patients (with active cancer or disease in remission). On average, 10.5 cancer patients (SD, 10.0) had contacts with their GP in 2014. From all the patients assigned to a single physician, 4.9% (SD, 4.4%) were cancer patients. During 2014, an average of 1.3 (SD, 1.6) cancer patients moved to nursing homes and 6.0 (SD, 5.7) died (all causes of death). Within a period of five working days, GPs had an average of 215.0 (SD, 75.2) patient contacts, from which 13.4 (SD, 11.0) were cancer patients.

### ***Survey findings on cancer patient characteristics and GP satisfaction with hospital and community level care provision***

More than half (58.8%) of the cancer patients included in the study were female and their average age was 63.4 years (SD, 14.9). The majority of patients (87.6%) were diagnosed with cancer after 2005. For patients included in the study, time to diagnosis was an average of 5.7 weeks (SD, 4.8). The most common diagnosis was malignant neoplasm of breast, affecting nearly a quarter of the cancer patients in the study (23.4%). Among the common diagnoses were malignant neoplasms of digestive organs (22.1%), malignant neoplasms of male genital organs (9.7%), malignant neoplasms of female genital organs (8.4%) and melanoma and other malignant neoplasms of skin (8.4%). Patients contacted their GP on average 10 times (SD, 9.6) in the year before the study. The majority of visits (6.2; SD, 6.6) were of administrative nature and consisted of issues such as issuing prescriptions, referrals and medical device ordinances. Less frequently, the purpose of the visits was for coordination of health care services (2.0; SD, 3.6), consultation with relatives (1.9; SD, 6.0) and psychosocial support (1.6; SD, 3.0). Coordination of social services, help with activities of daily living, palliative care and home care were seldom topics of GP visits. Disability evaluation was not undertaken frequently because the majority of the patients were no longer in active employment.

GPs were mostly satisfied (5.6 to 4.1 on a 7-point Likert scale) with patient treatment at primary and secondary care levels, existing guidelines, diagnostics possibilities, accessibility of services at the secondary care level, accessibility of pharmacological pain management and with information transfer from specialists to GP. They were somewhat dissatisfied (from 3.1 to 2.1) with medical on-call services, inclusion of family members in treatment process and with communication with specialists involved in cancer patient treatment. They were mostly dissatisfied with palliative care, willingness of other services to be involved in cancer patient treatment, accessibility of non-

pharmacological management of pain and other symptoms, organized home care and with community care services. GPs were most dissatisfied (from 1.9 to 0.4) with availability, involvement and coordination of community and social care services. However, patients seldom used these services.

### ***Interview results***

Findings from the interviews in May and June 2015 showed that physicians experience high levels of stress particularly in the early phases of cancer patient care – from time suspicion of cancer is established to time of cancer therapy initiation. In order to shorten the time before the patient with a suspicion of cancer receives diagnostic tests, GPs have to coordinate health care services. Physicians reported lack of “fast track” for suspected cancer patients, particularly in cases based on an agreement between GP and specialist. They would also value a possibility of consultation with a specialist in cases of suspicion of cancer where future management is unclear. Patients rarely meet their GP while being treated at the Institute of Oncology, which scored high in satisfaction with the treatment delivered as perceived by the GPs. While cancer patients are treated in ambulatory settings, more contacts are needed with their family members than with the patients themselves. GPs emphasized the importance of cooperation with different health care service (community care, patient transport services) during the ambulatory cancer treatment phase. GPs did not report special needs or problems during the surveillance phase of cancer care. However, they did report that there should be more emphasis on full rehabilitation of the patient, including psychosocial support. Furthermore, the interviewed physicians reported that patients need more psychological support during the after-care period. Easier access/referral to psychotherapy would benefit patients, particularly in reducing fear of cancer recurrence, according to the GPs. Respondents reported that they had struggled with palliative care of patients in the past because of lack of knowledge but the palliative care area had improved vastly in recent years. They reported having numerous palliative care courses and a specialist of palliative care available for consultation. The latter is an exception occurring in the region of Slovenia from which the interviewed physicians originate (Upper Carniola).

### ***Development and testing recommendations***

An observational retrospective study included 13 out of 32 GPs (40.6% response rate), who had already participated in the first round of the study. Data on 63 cancer patients and their treatments were collected and evaluated. Activities, most frequently performed (over 70%) included general and psychological support as well as good communication skills and care for concomitant chronic diseases. Elaboration of a written treatment and pain management plan, coordination with other community services and psychosocial rehabilitation plan were less frequent activities (under 15%). In general, there was less need for assessment of occupational disability (in 23% of patients), because most patients were already retired. Among those of working age, more than half were involved in activities related to occupational assessment and rehabilitation. GPs evaluated good practice recommendations as a useful, although sometimes too general, tool in cancer after-care; however they emphasized time shortages in comprehensive after-care. Suggestions were raised that nurses could also take part in cancer after-care.

In summary, GPs in Slovenia have an increasingly important role in the after-care of surviving cancer patients with the majority of contacts occurring for administrative reasons. However, GPs experience high burden of stress during the initial phases of a patient’s disease as well as later during after-care. Cancer patient pathway (i.e. good practice recommendations) was recognized as valuable tool for systematic approach to patients with cancer during after-care.

## The Norwegian experience: the development of an integrated care pathway (the Orkdal model)

Norway decided in 2013 to strengthen the coordination of care at the regional level and introduce integrated care pathways (ICP) as a method to implement this integration into clinical practice; ICPs are structured multidisciplinary care plans that can facilitate a process by which palliative care and oncology can be integrated in a given setting. ICPs may provide a process plan, provide a time frame, describe the type of expertise needed at any step in the process and describe the resources needed during the trajectory (13,14). A recent Cochrane review concluded that ICPs reduce hospital complexity and improve documentation without having any negative impact on length of stay or hospital cost (15).

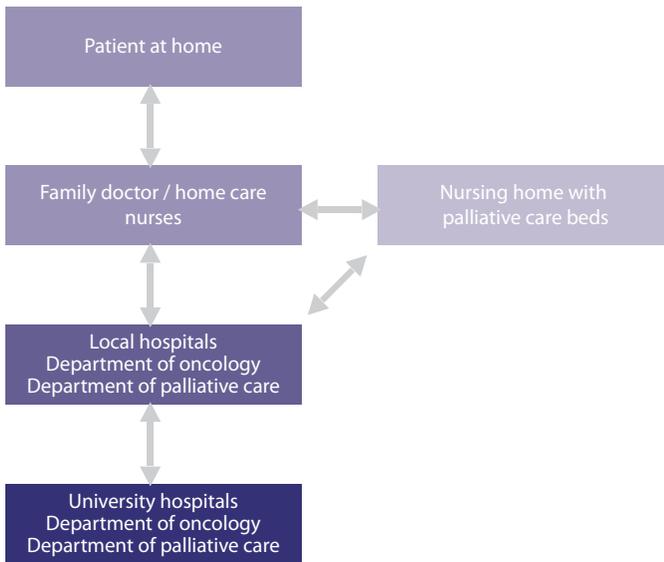
### *The ICP*

The main component of the Orkdal model is an ICP that facilitates evidence-based practice, improves coordination of care in all phases of the disease trajectory, and integrates oncology and palliative care. The care pathway is to be applied regardless of cancer diagnosis, focusing on function, needs and symptoms, and it covers health care services in home care, nursing homes and specialist care. Symptom assessment and optimal symptom management, definition of responsibilities, optimal communication and access to cancer care services whenever needed constitute the core of the pathway. Overall, the development and use of the ICPs contributes to ensure:

- **quality** of palliative care offered (equal quality of care regardless of level);
- **responsibility** in that there is a clear definition of which health care professional is responsible for the patient at different points in time (defining the right level of care);
- **flexibility** as the patient's needs vary during the disease trajectory and may often be difficult to predict; and
- **availability** of health care services 24 hours a day/seven days a week in order to ensure safety and quality for patients and carers.

The Norwegian model for comprehensive cancer care is the basis of the ICP where GPs (with a gate-keeping role) and home-care nurses are responsible for the visiting, treating and caring of the patient at home and in community care settings (16). Specialists are available for the GPs for supervision. Patients' needs are considered in a step-up model: the first option considered is the local nursing home with specialized oncology/palliative care, then local hospital care and finally, for highly selected patients, university hospital care (Fig. 6.6). Necessary templates, checklists, assessment tools, contact information and relevant guidelines are included in the ICP. Electronic assessment of patient-reported outcomes is partially applied in the project.

**Fig. 6.6** Norwegian comprehensive cancer care



**Educational programme**

To implement the ICP, an educational programme in oncology and palliative care is offered to the providers, mainly to physicians, nurses, and nurse assistants. Participants are encouraged to teach colleagues at their respective place of work. Resource cancer nurses organized in a network have extra responsibility for teaching and for implementing the model locally. Project positions for GPs and community cancer nurses have been offered at the outpatient clinics to achieve specialist competence in community care. A master’s programme in pain and palliative care has been established at the Norwegian University of Science and Technology, Trondheim.

**Information for citizens**

Through the project, patients, carers and the public are offered information regarding chemo- and radiotherapy, symptom diagnosis and treatment, available expertise, volunteers, educational courses for patients and carers, and who to contact. The information is given as written materials, electronically and at public meetings. Educating patients in systematically reporting of needs and symptoms and about available oncology and palliative services is important to achieve high-quality care where the patient is actively taking part in treatment decisions and planning of their care.

**Advantages of the integrated cancer care pathway**

The care pathway increases the quality of care (17). Some of the experienced advantages (17–20) that have been identified so far in the participating municipalities are:

- systematic symptom assessment and evaluation of different treatments according to the patient reported symptoms, function and needs;
- higher degree of collaboration and better coordination of services, including fewer unnecessary consultations and better planning of what services the individual patient and family may need;
- clarification of treatment intention and a clear treatment plan;

- fewer unnecessary potential toxic anticancer treatments;
- medication lists updated more often;;
- improved communication between health care providers across levels of care, including better written reports that are available at the time of change of place of care;
- improved communication between health care providers and the patient;
- improved communication between health care providers and the carers; and
- support from management in the specialist and community care needed to succeed with implementation.

### ***Advantages of the educational programme***

After participating at courses focusing on integrated cancer care, the GPs are more aware of the cancer patients and their potential needs for closer follow-up in all phases of their disease (i.e. after being cured, living with metastatic disease and at the end of life). PCPs in community care are more aware of further available expertise locally and in specialist care. Because they have support from specialist care, they are to a larger extent able to take more responsibility locally and for patients with complex cancer. GPs and cancer nurses educated thorough project positions at the outpatient clinic now working locally and are providing specialist competence at community care level, which is made possible through more health care providers locally having more knowledge in oncology and palliative care. Consequently, oncologists are able to spend their time specifically on oncological treatment and the most complex disorders. Furthermore, fewer hospitalizations may be needed and potential toxic anticancer treatment might be stopped earlier or largely not started when appropriate.

### ***Advantages of information for citizens***

Better-informed patients and families make in many cases better treatment decisions and improve communication. The patients may feel more confident and that the disease trajectory is more predictable. Patients may report symptoms more reliable and may be better educated to ask for available services such as appropriate treatment for pain and nausea or advice from a social worker.

In summary, the ICP, educational programmes for PCPs and information delivered to citizens increase quality of care, improve communication across levels of care and with patients and contribute to better treatment decisions.

## **The Netherlands: the role of primary care in after-care for cancer**

In 2013 and 2014, NIVEL published a series of papers based on studies that analysed the characteristics of cancer patients in primary care, the resulting workload and the consequent impact on the development of these services at the primary care level in the Netherlands. Key findings of these studies are summarized below.

### ***Primary care for cancer survivors***

While Dutch GPs have no formal role in follow-up visits in the first five years after diagnosis of cancer, they are involved in care for cancer survivors. As many cancer patients are older and have chronic diseases in addition to cancer, they visit their GP for various other health problems. At the end of the follow-up visits with the medical specialist, GPs take over the care for patients.

The number of cancer survivors per GP practice is considerable. In an average practice of 2350 listed patients (1.0 full-time equivalent GP), about 70 patients had been diagnosed with cancer less than nine years previously (21). Cancer survivors have more GP contacts than those of the same age and sex without cancer (Table 6.7). In the first years after diagnosis, cancer survivors have a higher number of office visits and telephone consultations and the GP more often pays home visits. Cancer survivors also have a higher number of medication prescriptions and referrals to secondary care (22–25). Patients who are over 60 years of age and have been treated with breast-conserving surgery may be referred to their GP for yearly follow-up visits, with a mammography every two years. After the initial treatment for prostate cancer, clinical examination and PSA measurement are recommended after six weeks, at three, six and 12 months, and then every six months for the three years after diagnosis and annually from five to 10 years. After five years, patients with stable low PSA levels may be referred to the GP.

**Table 6.7** Mean number of GP contacts per year in Dutch cancer survivors compared with age- and sex-matched controls without cancer from the same GP practice

	Breast cancer		Prostate cancer		Colorectal cancer		All types of cancer <sup>c</sup>	
	Survivor	Control	Survivor	Control	Survivor	Control	Survivor	Control
Practice visits	3.3–4.0 <sup>ab</sup>	2.9–3.2 <sup>ab</sup>	3.6	2.9	3.5	3.0	3.5	2.7
Telephone	0.8	0.4	1.2	0.7	1.2	0.8	–	–
Home visit	1.2	0.9	1.1	0.7	1.2	1.0	1.6	0.4
Total	5.3–6.0	4.2–4.5	5.9	4.3	5.9	4.8		

<sup>a</sup>Breast, prostate and colorectal cancer 2–5 years after diagnosis (22); <sup>b</sup>breast cancer a median of 1 year after diagnosis (25); <sup>c</sup>all cancer types at less than 6 months after diagnosis (23).

The number of GP contacts varies widely between patients. As expected, older patients and those with a chronic disease have the highest number of GP contacts. Cancer survivors aged 50 years without a chronic disease have, on average, three to four GP contacts per year, while those aged 80 with a chronic disease have, on average, eight to nine contacts per year. The increase in the number of GP contacts with age and with the number of chronic diseases is similar in cancer survivors and controls without cancer (26).

### **Health problems for which cancer survivors visit their GP**

The health problems for which cancer survivors visit their GP differ by cancer type. Breast cancer survivors visit their GP more often for acute symptoms, such as back or abdominal pain, in the period of two to five years after diagnosis. They also visit the GP more frequently for common infections, such as cystitis or respiratory infections (27). The GP also frequently take over the management of hormone or aromatase inhibitor use, which was originally initiated by a specialist. Although breast cancer survivors do not visit their GP more often for psychosocial problems, GPs more often prescribe psychomedication to these patients.

In the two to five years after diagnosis, prostate cancer survivors visit their GP more often for general symptoms, such as fatigue, constipation and back pain, but surprisingly not for urinary incontinence or erectile dysfunction. Colorectal cancer survivors visit their GP more often for infections, such as skin or urinary infections, but also because of anaemia, abdominal pain and side-effects of treatment.

In conclusion, cancer survivors visit their GP more often for common acute symptoms, such as fatigue, pain and common infections. This may be related to late effects of cancer treatment. Both fatigue and pain often develop during treatment and may persist thereafter. Infections may occur because of a weakened immune system. Alternatively, cancer survivors may be more prone to visit their GP for these relatively common symptoms because of increased health concerns. The number of GP contacts related to chronic diseases and psychosocial problems is slightly higher in cancer survivors but is not a major cause for the increase in health care use.

### **Estimated increase of GP contacts in the Netherlands in the future**

Following the increasing incidence of cancer and improving survival for cancer, it is expected that the number of patients living with cancer in the Netherlands will increase from 419 000 in 2009 to 666 000 in 2020 (28). As these patients frequently contact their GP, this will also lead to an increase in GP contacts. Researchers from NIVEL have estimated the rise in contacts will follow two scenarios. The first scenario takes into account the estimated increase in the number of cancer survivors. The second scenario also takes into account the current debate to increase the role of the GP for after-care. GPs are already involved in care for these patients; they often see these patients for chronic diseases besides cancer and their practices are usually near to their patients' residences. It is, therefore, suggested that part of after-care should be transferred from the specialist to the GP. In the second scenario it is assumed that this will lead to two additional GP contacts per year. In Table 6.8, the estimated number of contacts in the Netherlands and the number of contacts for a standard GP practice (with 2350 listed patients) is given (29). It is estimated that in 2020 a standard GP practice will have 850–1100 contacts with cancer survivors, about 20 contacts per week. This is an increase of 70–120% compared with 2010.

**Table 6.8** Number of contacts per year that GPs have with cancer survivors in the Netherlands

	2010	2020: based on increase in patients	2020: based on increase in patients + 2 contacts per year from specialist care
Total	3 600 000	6 000 000	7 600 000
Per norm practice (2 350 patients)	500	850	1 100

Source: Signaleringscommissie KWF (29).

In summary, GPs in the Netherlands have an important role in the after-care of surviving cancer patients, as demonstrated by the higher number of contacts compared with patients without cancer. Cancer patients visit their GP for common health problems. With the increasing number of surviving cancer patients, GPs might be also involved in the future in oncological after-care for surviving cancer patients.

### **Denmark: organization of cancer after-care in primary care settings**

In Denmark, a reform of after-care is in progress, following reports of waste caused by unnecessary oncological hospital-based follow-up of cancer survivors. This reform also comes out of need for rational use of the resources in cancer care before an expected increase in cancer patients caused by the ageing population. The main characteristics of this ongoing reform process are described below.

### ***The working process and timeline***

Following discussions in 2010–2012 on the need for a reform in cancer after-care, the decision to reform was taken in 2012. In 2013, a specified working plan was agreed where the Danish Health Authority would chair a series of working groups that would describe the follow-up for each main type of cancer. These plans on follow-up care would be worked out in collaboration with relevant administrative and clinical stakeholders (the multidisciplinary national cancer groups) including representatives from general practice. The plans would be amendment to the already created national fast track system for diagnosis and treatment of each cancer. The implementation of the reform was scheduled for the end of 2015 and the beginning of 2016.

### ***The content of each plan***

Each plan would follow a standardized scheme and it was printed (some 30–40 pages) and put on the web by the National Board of Health (30). The following items would be addressed in each plan:

- an individual needs assessment for each patient and clear agreement with each patient about the follow-up plan following completed primary treatment;
- description of symptoms and signs of recurrence and strategy to identify recurrence;
- rehabilitation and palliation assessment and planning;
- psychosocial, spiritual and existential considerations including ways to empower patients and involve them; and
- the evidence base for the recommendations in each guideline would be identified.

### ***Implementation in 2016***

Fourteen groups have developed 19 new guidelines with eight in the implementation phase. The five regions, which are also the hospital owners, have a strong focus on the implementation process, which they try to follow in a nationally agreed form. There are still not confirmed agreements on information technology monitoring and monitoring of the process. Each plan has a description of some sort of a stratified approach with tasks for specialists, nurses in hospital and for GPs.

The implementation will follow three steps.

- 1 Breast, gynaecological cancers, colorectal cancer and prostate cancer (under implementation)
- 2 Head and neck, brain, sarcoma, melanoma
- 3 The rest of cancers.

There is still no agreed work plan and payment plan for GPs involvement, but it is anticipated that they only will be involved to a larger degree in prostate cancer and for the other cancers; their role will probably be patient attendance on an ad hoc need-based way. There is no specific agreement for how to establish an integrated trajectory as patients will be (for now) regarded as oncological patients and not transferred/referred to primary care. There is no specific agreement on how GPs may access specialized services, including fast and direct investigation methods and help from consultants.

### **Bulgaria: organization of cancer after-care in regional cancer centres**

Follow-up of patients within the Bulgarian health care system is part of the development and implementation of activities and services within the framework of a more comprehensive

approach to cancer concentrated within specialists' expertise in comprehensive cancer centres, not within primary care. In this setting, how do comprehensive cancer centres deliver after-care and are patients and professionals satisfied with this arrangement?

Seven comprehensive cancer centres were approached and four of them returned completed questionnaires: Sofia, Veliko Tynovo, Burgas and Stara Zagora (detailed information from the questionnaires is provided as supplemental information at [www.cancercontrol.eu](http://www.cancercontrol.eu)). The results indicate the small number of doctors working within a comprehensive cancer centre in comparison with the very high numbers of patients and examinations conducted. Despite the fact that consultation with relatives is part of a clinician's practice, provision of psychosocial care within the centres is usually lacking. In relation to coordination of health services and social services, comprehensive cancer centres are not reported to have such responsibilities.

Comparison of data on doctors' and patients' experiences indicates several significant differences. There is a gap between the satisfaction expressed by doctors and that by patients. When asked about their experience of treatment of oncological patients at the secondary level, patients were largely satisfied, while the doctors were dissatisfied. The same discrepancy emerged in terms of participation of other services in the treatment of patients. Organized home care (when needed) was considered unsatisfactory by the doctors, while for patients it was satisfactory. Doctors felt that the involvement of family members in the care of the patient and the role of the community social care services were areas that would need further improvement (overall reported as being neither satisfied, nor dissatisfied) whereas these two topics were reported as being satisfactory in terms of patients' experience.

When comparing results from doctors and cancer patients, it was established that there are some clear similarities, such as satisfaction on existing guidelines, availability of pharmacological substances for pain relief, communication of clinical specialists in after-care and replacement in case of absence. The specific characteristics of the health care system and the role of GPs in oncological treatment and after-care were evident in the level of dissatisfaction about issues of treatment of oncological patients at the primary level experienced both by the doctors and by the patients.

The qualitative interviews showed that GPs consider the provided after-care for cancer patients as being inadequate and the patients' needs unmet (in terms of psychological and social support and the feeling of isolation in the process of treatment). In terms of patients' experience, there is a strong assumption about feelings of dissatisfaction as usually the patient has to wait for treatment and after-care because of the large number of cancer patients and the limited number of medical specialists; consequently, this situation causes more distress. Moreover, it is a huge obstacle for the patients to remain in employment and to keep up the "unnecessary" bureaucratic procedure related to it.

The prospect of engaging the GPs within the process of after-care is not considered a possibility. In reality, doctors' expectations of primary care are regular monitoring and home care of cancer patients, assistance in diagnosis and better electronic communication. Doctors feel that within the primary levels, GPs have to provide services such as examinations, psychosocial care, home care, help with the activities of daily living, prescriptions, planning of care and working disability assessment. Other experts and organization should assist in issues of palliative care, coordination of health and social services and family consultations.

## Discussion

The changing developments in cancer diagnosis result in a growing number of people who survive cancer (31). As a result, the role of after-care is becoming increasingly important, but also challenging from the point of view of the volume of this care. Oncologists in hospitals often provide cancer after-care (32) but are facing challenges, such as limited hospital capacity and increasing patient numbers. At the health policy level, there are pressures to substitute care by replacing specialist-led care by GP-led care. Consequently, there are increasing calls for greater involvement of GPs in the after-care of cancer survivors. To give PCPs a greater role, however, raises the question of what information and resources GPs can draw on to provide after-care.

This chapter give an overview of evidence- and opinion-based recommendations on after-care for cancer survivors that are (potentially) relevant for GPs. Guidelines on the five most common tumour types were studied and information on three categories – recurrence detection, long-term effects and recurrence prevention – was provided for all tumour types. The inventory highlights that there is not always sufficient evidence on the best way to provide after-care nor conclusive proof about the optimal frequency of after-care diagnostic testing. Furthermore, most information provided by guidelines was not evidence based, indicating a need for research on after-care for cancer survivors. There is a clear need to improve guidelines with respect to the different providers who are increasingly involved in after-care as well as training of GPs and other PCPs, because they will face rising patient needs that will realistically be covered only by the PCPs.

The chapter also presents an overview of national and regional practices on how cancer after-care is organized in Bulgaria, Denmark, the Netherlands, Norway and Slovenia. Four of these countries have a GP-gate-keeping system and a strong role of community care, including in the cancer after-care process. Only in Bulgaria does after-care remain the task of cancer hospitals.

In Slovenia, GPs coordinate health care services during the early diagnostic period of cancer patient care. Later, patients rarely meet their GP while being treated at the specialist centres. In after-care, the majority of clinical visits are of administrative nature, but they also include coordination of health care services, consultation with relatives and psychosocial support. GPs emphasized the importance of cooperation with different health care services during all phases of cancer care.

Norwegian experience is based on ICPs that facilitates evidence-based practice, coordination of care and integration between oncology and palliative care. Use of ICPs contributes to quality of care, clear definition of responsibilities, a flexible approach to patient's needs and availability of services. The care pathway involves home care, nursing homes and specialist care.

Dutch GPs are involved in the care for cancer survivors not earlier than five years after diagnosis of cancer. They provide consultations for common problems or late effects of cancer treatment. Cancer survivors have more GP contacts than patients without cancer.

In Denmark, a reform of after-care is in progress. It is expected that plans on follow-up care will be prepared for each main type of cancer. Involvement of GPs in planned after-care is not yet agreed and GPs will probably see patients on an ad hoc needs-based way.

After-care in Bulgaria is provided in comprehensive cancer centres. Coordination with home and social care services is often poor, although patients feel satisfied with it. Stronger involvement of GPs is not considered as a relevant option.

The five different country cases have only few elements of cancer after-care in common. Countries with GP-based system implemented comprehensive (e.g. Norway, Denmark) or fragmented (e.g. Slovenia) mechanisms of coordination across levels of care. These mechanisms range from a full integration model (e.g. Orkdal model, Danish reform), where care pathways link providers, professionals and services around patient needs, to a fragmented approach, where coordination of care is a matter of GP's core competencies rather than systematic (e.g. Slovenia). Dutch experience fits between these two. Bulgaria, as an example of a country with centralized cancer care, struggles with scarce resources and after-care is not at the top of the agenda.

All these challenges are important, as is the need for sharing all patient information and developing joint files. Seamless care requires proper access to all data and information through linkages between clinical data and outpatient and primary care data and registries. Such an approach would be helpful in providing continuity and comprehensive information for everyone involved in continued cancer care.

## Conclusions and recommendations

Europe presents a wide variety of approaches in the organization of cancer after-care. In many cases, hospitals and oncological services at the in- and outpatient level continue to provide a large part of after-care. Under such circumstances, the role of PCPs remains supportive to the process and important in terms of securing all the other services and for integration with other sectors to cover issues such as patients' employment and material and psychological needs. PCPs also need to ensure proper care for other chronic conditions that these patients may have at the time of the cancer diagnosis or that may be diagnosed later. Such patients will inevitably become frequent users of community care services. Nevertheless, as cancer incidence continues to increase, and modern oncological care becomes ever more specialized, focused and intense, the question arises as to how high-quality after-care and long-term supervision for stable patients in remission can be organized while taking their diverse needs and expectations, as well as cost-effectiveness, into account. Cancer is a specific noncommunicable disease that can be successfully treated and cured, unlike most of the other noncommunicable diseases. This means that overcoming cancer is a reality and leads (former) patients, their carers and the professional staff treating and monitoring them into new challenges related to survivorship.

In this exploration of cancer after-care services and the typology of providers, the experiences of five different countries were examined, some of which were going through a transformation of their existing practices. The selection of countries depended on the willingness of their respective ministries of health and the representative institutions to participate, and not on any predefined set of criteria. Nevertheless, we believe that this insight into after-care practices provides valuable insight into the current state of after-care as well as for the potential for improvements. Our objective was to propose a blueprint for a cancer patient pathway in after-care. After the survey on after-care in EU Member States, and also based on some previous experience in the participating countries, it became clear that such a pathway would not be feasible. Health care systems, the modalities and mechanisms of their financing and the traditions across countries vary importantly and do not allow for a higher level of uniformity. In spite of this conclusion, we believe that the contributions from the participating countries are important for the following reasons.

- We have been able to obtain clear and comprehensive data on the existence and applicability of guidelines for after-care and discovered both discrepancies in information and guidance as well as in the provision of after-care.
- We could identify the need to dedicate more time to the development of prevention guidelines for cancer survivors, focusing particularly on secondary and tertiary prevention, while not forgetting about health determinants.
- We have explored five countries with different approaches to after-care and which are at different stages in the transition from hospital to primary care:
  - Bulgaria, where provision of after-care is limited to cancer centres, which is a model that might work when both patient expectations and PCP's wishes are supporting such a choice;
  - the Netherlands, where important information on long-term challenges for PCP posed by cancer survivors are highlighted, including increased workloads, spousal and carer burden and additional training and knowledge needs;
  - Denmark, where a transition process, ongoing in 2016, is intended to integrate patient after-care among specialists, nurses in hospitals and GPs;
  - Norway, where a country with geographical challenges is trying to find ways to bring survivorship support, after-care and palliative care closer to where patients live (without losing the quality and efficiency of these types of care); and
  - Slovenia, where GP practices appear to be overwhelmed with the challenges presented by increasing numbers of with cancer patients but are developing elements of a future care pathway for after-care for cancer patients.

## Recommendations

This overview gives policy-makers/guideline developers the opportunity to discuss different after-care topic actions, tests and awareness, sometimes supplied with frequencies that could be included into their own guidelines on after-care for a specific tumour type. It also shows that preparing a comprehensive/integrated patient pathway is important for several reasons.

- seamless care is needed and expected; the care needs to be continued across the formal institutional boundaries;
- patient information is crucial; patients need to be fully and comprehensively informed about the processes related to their continued care; and
- guideline implementation is needed (when and where these are in place) to structure care around the evidence-based milestones (patient pathway represents a common tool for guideline implementation).

For the future development of cancer after-care we recommend the following.

- 1 Manage cancer as a continuous process where patients seamlessly pass (transit) different phases and stages. This can be achieved through the creation and updating of a cancer patient pathway going from screening outcomes through diagnostics and treatment to long-term

monitoring in remission, life-prolonging treatments and palliative and end-of-life care. It is important to:

- a/ reflect the current level of knowledge in cancer treatment but also the specifics of the country's health care system and its organization;
  - b/ secure the necessary resources, human, financial, equipment and medicines, at all stages of the pathway;
  - c/ develop the segment of the pathway for the cancer patients' after-care in close collaboration between specialized oncological care and PCPs; and
  - d/ organize an information exchange platform that enables all providers involved in cancer patient care to share the data and files relevant to the patient.
- 2 Organize the education and training for PCPs in order to strengthen their capacity to cope with the increasing population of cancer patients in after-care.
  - 3 Develop guidelines and guidance, at least for each of the most frequent cancers, on what to include and on what not to include in the long-term monitoring of patients (system specific, differences in access to some tests and diagnostics). This should include the following segments:
    - a/ recurrence detection, indicating the best frequency to perform diagnostic tests to detect cancer recurrence, the description of the signs and risk of recurrence in a given category of patients and, finally, defining and elaborating for the patients' after-care in terms of the responsibilities of GPs (in case they are willing to perform this role);
    - b/ long-term effects of cancer, where there should be more information on the potential complications of individual types and locations of cancer and how these should be prevented and treated; furthermore, more knowledge and recommendations on psychological support for cancer survivors are warranted; and
    - c/ recurrence prevention, where there should be more research into the value of recurrence prevention and specific recommendations for cancer survivors.
  - 4 Coordinate services between the health and other sectors for many patients not only for those who become disabled or are terminally ill. Treatment itself, long absences from work or treatment away from family may raise all sorts of problems (e.g. additional expenses or less productivity).

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# Survivorship and rehabilitation: policy recommendations for quality improvement in cancer survivorship and rehabilitation in EU Member States

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## Main messages

- 1 Cancer survivors' follow-up, late effect management and tertiary prevention needs to be anticipated, personalized and implemented into care pathways, with active participation of survivors and relatives.
- 2 Improvement of early detection of patients' needs and their access to rehabilitation, psychosocial and palliative care services is required.
- 3 An integrated and multiprofessional care approach with a coordination of community care providers and services are needed to implement a survivorship care plan that enhances patient's self-management and quality of life.
- 4 For children, adolescents and young adults survivors, late health and psychosocial effects of cancer and its treatments need to be anticipated and addressed.
- 5 More research in the area of survivorship is needed to provide data on late effects, as well as the impact and cost-effectiveness of supportive care, rehabilitation, palliative and psychosocial care interventions.

## Introduction

### The new cancer survivorship challenge: going beyond quality of care and ensuring quality of life

Over past decades, the number of cancer survivors has increased substantially in Europe as well as in most high-income countries, as a result of the ageing population, progress in early diagnosis and effectiveness of therapies. Survival from cancer is improving and the five-year global prevalence of all cancers in Europe was about 9.7 million people in 2012 (1).

However cancer survival still varies widely within Europe, with lower rates in eastern countries compared with Nordic and central European countries (2).

Whether being cured (disease-free) or not, cancer survivors do experience late and long-term effects of treatment, emotional distress and potentially tumour recurrence. These effects represent challenges for health care systems, which have to ensure their appropriate follow-up care and quality of life: moving from “how long” people live after diagnosis to “how well” people can expect to live from diagnosis onward.

Recognizing this, the Council of the European Union invited Member States to “take into account the psycho-social needs of patients and improve the quality of life for cancer patients through support, rehabilitation and palliative care” (3). Eurostat defines quality of life as “the functional capabilities that citizens should have available to effectively pursue their self-defined well-being, according to their own values and priorities” (4). The patient-centred approach is, therefore, of high importance in the planning of (any type of) care provision.

Many studies have investigated the issues in the follow-up care of cancer survivors (5–7) and found the most impeding factors for the quality of cancer follow-up care were poor coordination of care, lack of communication among health care providers, uncertainties about “who is responsible” for the follow-up care and occurrence of many psychosocial unmet needs.

Based on the Institute of Medicine recommendations (5), the (site-specific) templates developed by the American Society of Clinical Oncology for the follow-up care of cancer survivors recommended the use of survivorship care plans to overcome these issues (8). Despite great values, survivorship care plans are still scarcely used because of two main barriers (7,9): the feasibility of integrating them into practice and the human and financial resources required to develop and manage these plans.

At the moment, no clear consensus exists regarding the content, format, management and implementation of long-term follow-up care plans for cancer survivors. This chapter aims at reviewing the existing knowledge and evidence about these plans and at providing policy recommendations for health administrators and policy-makers in charge of cancer control in EU Member States, in order to facilitate or engage in the improvement of the quality of cancer survivor’s care and life.<sup>3</sup>

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## The definition of cancer survivorship

The cancer care pathway or continuum has evolved alongside treatment innovations, as did attempts to define cancer survivorship. First definitions were based on the three key phases of cancer treatment: patients recently diagnosed, patients who completed their treatment and experience periodic examinations and patients considered as “cured” (10). This can be summarized as “the experience of living with, through and beyond a diagnosis of cancer” (11).

Cancer treatment improvements implied the appearance of patients living cancer free for many years but who experience recurrence or develop second primary cancer, patients with intermittent periods of active disease (chronic cancers), patients living for many years with advanced cancers and those who live after the expected death (12).

For the purpose of this chapter, a cancer survivor is defined as anyone with a diagnosis of cancer and who is still alive. This includes patients having completed primary therapy and who are free of disease as well as those patients living with recurrent and/or advanced disease.

According to WHO (13), rehabilitation (though not cancer specific) is defined as “a process aimed at enabling them [people with disabilities] to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels.” In fact, cancer may be seen as a chronic illness with patients enduring physical and psychological symptoms years after treatment.

## A new paradigm to be integrated in the cancer care pathway

Several reviews and surveys have been conducted in order to identify the best model of care for improving the cancer survivor’s quality of care and quality of life (5,6,9). The best approach appears to be the use of survivorship care plans that include the provision of medical and nonmedical care. Two main models are used: the shared care model (see below) and specialized survivorship clinics (7). The choice of which to use mainly depends on the national health care system, including the role of primary care and the reimbursement scheme (insurance coverage).

Even though evidence shows the important added-value for patients, health care providers and health care systems from survivorship care plans, these plans are scarcely used and few cancer patients have access to one.

The provision of policy recommendations for the content, format, management and implementation of survivorship care plans in EU Member States is the main purpose of this chapter.

## Methods

Results of the preliminary work on existing guidelines or plans for long-term follow-up care for cancer patients reported that four countries can be recognized as pioneers: the United States, Canada and Australia, which follow the work achieved by the Institute of Medicine (5), and the United Kingdom (14).

Recommendations from the Institute of Medicine (5) for the United States and from the National Cancer Survivorship Initiative for the United Kingdom (14) and the content of their follow-up care plans were compared and five key areas were identified for investigation in the field of long-term follow-up care for cancer patients:

- medical follow-up: management of the late effects and tertiary prevention
- psychological support
- social rehabilitation including employment issues
- empowerment of cancer survivors
- multidisciplinary approach and coordination of care providers.

Four cross-cutting issues received particular attention:

- care for childhood cancer survivors
- inequalities in survivorship
- cancer information and data registration
- research.

In order to collect evidence about these nine issues and to translate it into policy recommendations for EU Member States, a three-fold methodology has been used (see supplemental information on methodology provided at [www.cancercontrol.eu](http://www.cancercontrol.eu)).

First, a literature review has been conducted using key words for the search and spread sheets to report outcomes.

Second, a critical appraisal exercise has been organized with a deliberative process involving invited EU experts to discuss the results and their applicability in EU Member States.

Third, in order to have insights into what is in use in EU Member States for cancer follow-up care, a survey was launched and 21 replies from nine EU countries have been analysed and compared (Annex 7.1).

## Results

### Content of long-term cancer follow-up care plans

A total of 151 publications (see supplemental information provided at [www.cancercontrol.eu](http://www.cancercontrol.eu)) have been retained and synthesized in the following to present key evidence related to the management of the late effects, tertiary prevention, psychological support and social rehabilitation in cancer follow-up care.

According to the National Cancer Institute in the United States (15), a survivorship care plan is “a detailed plan for a patient’s follow-up care after treatment for a disease ends. In cancer, the plan is based on the type of cancer and the treatment the patient received. A survivorship care plan may include schedules for physical exams and medical tests ... Follow-up care also checks for health problems that may occur months or years after treatment ends ... and may also include information to help meet the emotional, social, legal, and financial needs of the patient. It may include referrals to specialists and recommendations for a healthy lifestyle, such as changes in diet and exercise and quitting smoking.”

### Medical follow-up: management of late effects

Cancer and its treatment have both direct and indirect effects, such as treatment-induced cardiotoxicity (16–18), bone loss, fatigue, pain, depression, endocrine and fertility problems (19), and these are important elements for follow-up surveillance (7,20). The challenge is to identify the patients at risk of encountering late effects and thereafter use preventive measures to mitigate these effects as much as possible. Deterioration of physical, mental and social quality of life in survivorship is strongly connected to precarious situation (i.e. low income, unemployment and other socially disadvantageous positions) (21).

The evidence in the literature is incomplete for childhood, adolescent and young adult cancer survivorship. For this population, the late and long-term effects that negatively affect their health and well-being include cardiovascular diseases, neurocognitive functioning (22), sexual and reproductive functions (23) and renal and endocrine functions.

Findings suggest that there is a need for deeper understanding of factors associated with increased morbidity susceptibility. This means that elements such as genomics, personalized and behavioural medicine, treatment-related toxicities, psychology, cardiology and endocrinology, as well as genetic predisposition, should be examined (24). The relationships between cancer treatments and the natural ageing process, as well as the interaction of multiple morbidities, are issues that should be further explored (25).

### Medical follow-up: tertiary prevention

According to the IARC, tertiary prevention is “the use of treatment and rehabilitation programmes to improve the outcome of illness among affected individuals” (26).

Healthy lifestyle has positive effects on the prevention and management of late effects and cancer recurrence (5,27). Healthy food, adequate physical activity (28,29), avoidance of excessive sun exposure, limited alcohol consumption, stress reduction (30) and smoking cessation are important elements to consider for increased and quality survival.

Some physical activity is better than none and exercise can safely be undertaken by all cancer patients even during the advanced stage of the disease (31). Physical activity during treatment has shown to increase the percentage of patients completing therapy (32,33). It is effective in reducing both physiological and psychological treatment-related effects; speeds up recovery after treatment; improves pain in neck, shoulder and axillary region in breast cancer (34); and may prevent cancer recurrence (35,36). Incontinence, fatigue, body constitution and quality of life can be improved by physical exercise for patients during and after prostate cancer (37).

Stress is considered a risk factor for cancer recurrence. Stress-management interventions have been proved to reduce mortality and, therefore, may be beneficial in the prevention of recurrence (38,39).

### Survivorship care for patients with advanced cancer

Medical advances have enabled cancer patients to live longer with active advanced-stage diseases. Although the symptoms and medical needs are similar to those of disease-free survivors, psychosocial concerns are different (40).

Most publications address the early integration of supportive and palliative care into cancer care pathways of patients diagnosed with advanced cancers (41–44).

Alongside the symptoms and side-effects of cancer treatment (e.g. incontinence, neuropathy, hair loss, nausea), patients with advanced-stage disease have to face physical and psychological well-being fluctuations that have a disruptive impact on their ability and willingness to cope with treatment and to plan for the future (45).

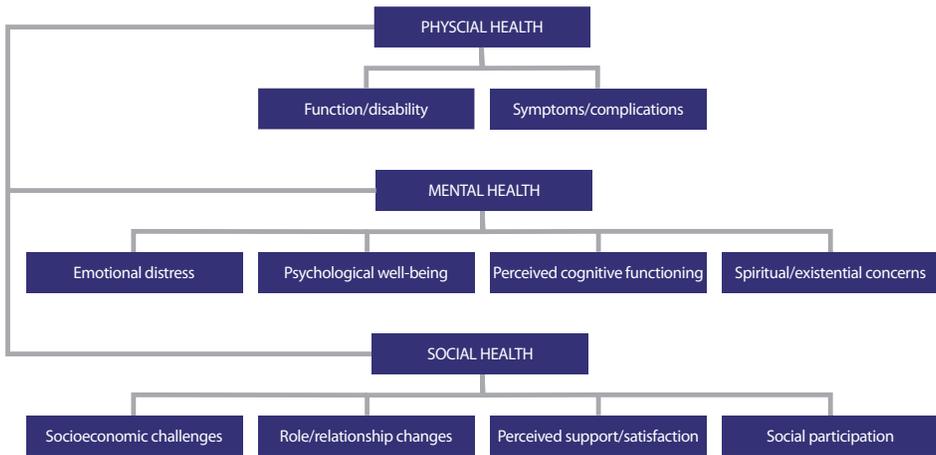
As for disease-free survivors, patients with advanced cancer report many unmet psychosocial needs but also additional unmet information needs, particularly related to euthanasia, living wills, financial and legal issue and hospices (46,47).

**Patient-centred approach for long-term follow-up**  
***Multidimensional needs’ assessment as the starting point***

The literature review showed that early and systematic detection of needs (Annex 7.2) in psychological support, social and physical rehabilitation, supportive and palliative care are necessary in order to orientate patients towards tailored health care interventions (48–50). It also demonstrated the necessity to anticipate certain issues that the patients and their relatives will face during the survivorship and rehabilitation period.

Measuring health-related quality of life should be integrated as an early, systematic and recurrent step in the long-term follow-up care of cancer survivors (51) (Fig. 7.1). Several tools already exist and can be used routinely.

**Fig. 7.1 Health-related quality of life in cancer survivors**



Source: Victorson et al., 2006 (51).

***Psychological support***

Diagnosis of cancer often generates major distress for patients and their families. Depression and other symptoms that impact quality of life during the entire cancer pathway are well documented, particularly among breast cancer survivors (52). Reviews highlight problems with fear of recurrence, fatigue, sexual health, depressive symptoms, pain and late or long-term effects because of cancer treatments. Individuals follow various trajectories of psychological adjustment during survivorship (53).

Evidence shows that psychological interventions reduce psychological morbidity and improve patients' adjustment to illness, quality of care and well-being (54–56). The access to psychological intervention during survivorship can be difficult, either because of patients' reluctance or because insufficient care is offered (57). Instruments for diagnosing psychosocial conditions, level of distress and psychosocial needs are not yet routinely used in all cancer settings (50,58). Several countries in Europe, the United States, Canada and Australia have developed clinical practice guidelines that assist clinicians in using evidence-based psychosocial care in their practice (49,59–62).

Inequalities are rarely mentioned in the selected articles from the review. However, geographical and social isolation may create greater difficulties in accessing quality psychosocial and palliative care for those living in rural areas and diagnosed with cancer (63). The mapping of psychosocial care resources in Europe shows that the provision of psycho-oncology services is very diverse, irregular and greatly depends on whether or not a country and its national cancer control plan or strategy considers psychosocial care as an element of multidisciplinary cancer care (64). Resources in this area are still scarce and widely variable across countries and type of hospital (cancer centre versus local hospital), mainly because of lack of financing and policy; in some countries they are even non-existent (65).

### **Professional reintegration**

Results include issues such as employment and insurance that cancer patients have to face (5,66,67). The case study based on the VICAN 2 survey (68) illustrates these issues (Box 7.1).

#### **Box 7.1 Case study examining employment issues: the VICAN 2 study**

##### **Background**

The French national study VICAN 2 sheds light on people's daily life and the impact of cancer during the survivorship and rehabilitation period. This case study focuses on the inequalities on both the occupation rate and income two years after the first diagnosis of cancer.

##### **Methodology**

Computer-assisted telephone interviews of 40 minutes duration were conducted between January 2012 and June 2013 with about 4350 patients who had been diagnosed with cancer in 2010.

##### **Outcome: cancer impact on income**

At the diagnosis stage in 2010, 20.9% could be considered as poor compared with 14% in the general population (data from the French National Institute for Statistics and Economic Studies). Two years after the diagnosis, the gap had increased, with 25.1% of people living with a cancer being below the poverty threshold compared with 14.3% of the general population.

Losing one's job is not the only way the diagnosis of cancer has a financial impact on household income: most of the people who continued their employment during cancer diagnosis, treatment and survivorship had to face various important changes in their working time depending on their health status, which had impact on their income.

## **Outcome: professional situation two years after diagnosis of cancer**

The professional situation of people diagnosed with cancer was shown to have considerably deteriorated two years after the diagnosis, with an activity rate decreasing from 88.2% in 2010 to 79.9% in 2012. The employment rate decreased to 61.3% and the unemployment rate was 11.1% (i.e. four points higher compared with 2010).

The most vulnerable people were mainly manual workers; the youngest and oldest; married people; people with an educational level below advanced level (A-level); those with fixed-term precarious working contracts; and those working in small and medium enterprises. This demonstrates a "double penalty", which brings together the unfavourable characteristics of the job market and the impact of the cancer diagnosis.

Most of the people aged between 18 and 57 years had lost their job 15 months after the diagnosis (91.6%) and 21.8% lost it at the moment of diagnosis. The waiting period before finding a new job was 11 months on average (i.e. an additional delay of 6 months compared with data for the general population).

### **Further research**

A similar national study with the same methodology will be launched to assess people's quality of life 5 years after the diagnosis.

### **Recommendation**

Similar studies should be conducted in different EU countries to better assess the impact of cancer on people's daily lives in order to address their needs and target sources of inequalities.

*Source:* Institut National du Cancer, 2014 (68).

Return-to-work support should be integrated early into the cancer care pathway, exploring the feasibility of adequate or progressive return to work and discussing with employers about working conditions (69,70). Both health care providers and employers have a role to play (63,71,72).

A strong emphasis is put on the positive effects of early psychosocial interventions in supporting cancer survivors with employment-related issues, ideally immediately after diagnosis and during treatment (73). Psychosocial and vocational rehabilitation need to take a person-centred approach based on each individual's situation: diagnosis and prognosis, medical and nonmedical treatments, intra- and interpersonal factors, patient values, aspirations and priorities, the attitude of colleagues, job demands, and so on. These determinants should be taken into account when planning reintegration into the working environment (70,74–79).

Supportive return-to-work interventions can be directed to employees or to the work environment and employers (80–82). The first approach aims at maintaining or enhancing the employability of cancer survivors. Work environment-directed interventions aim at adapting workplace environment, equipment, tasks and working time patterns to the needs of the cancer survivor. More evidence is needed on the effectiveness of return-to-work interventions and on work conditions for cancer survivors who do return to work (83).

Regarding employment and return-to-work issues, there are some good examples of regulation for the protection of cancer survivors and their relatives.

An Italian regulation passed in 2003 (decree-law n° 276/2003, article 46, as amendment of decree-law n° 61/2000, article 12 bis) prescribed the right for cancer patients working in the private sector to switch from full-time to part-time positions while under treatment, and to reverse to full-time according to their needs and capability. The same right was extended to public employees in 2007 (law n° 247/2007, article 1, subsection 44). Within the same legal framework, relatives (caregivers) of cancer patients are given priority over part-time applications as long as there are positions available.

In the United Kingdom, the employment provisions of the Equality Act 2010 protect anyone who has, or has had, a disability (including people affected by cancer). The Act requires employers to make reasonable adjustments for employees with a disability. But it also includes important provisions to prevent discrimination arising from disability, indirect discrimination and discrimination against carers.

Other socioeconomic issues relate to health, disability and life insurances. European surveys (84) and the Institute of Medicine study (5) have reported that psychosocial workers should provide information on the potential insurance, employment and financial consequences of cancer through provision of a directory of cancer-related resources (e.g. online or telephone listings) and/or information in the form of general information brochures. Raising these issues with patients will at least let them know that help is available.

### ***Children, adolescents and young adult survivors of cancer***

For children, adolescents and young adults, the psychosocial experience of the illness is highly variable (85,86). It is sometimes years after the cancer is cured that the psychosocial impact of the illness occurs, leading to requests for support and psychosocial care (87,88). The utility of supportive and rehabilitation care has been proved, in particular adapted physical activity for children, to be associated with better health-related quality of life (89,90).

The literature suggests a routine yearly psychosocial assessment with attention to behavioural issues and educational and/or vocational progress to detect early signs of psychosocial suffering (91,92). Parents or relatives need to be involved in every step and are always considered as facilitators if they are properly educated, informed and coached by the health care providers (93).

## **Management of long-term follow-up care plans**

Results from 55 publications have been retained, synthesized and discussed in order to present the key evidence regarding the management of survivorship care plans. There were three main issues: the role of multidisciplinary teams and the coordination of providers; the empowerment of cancer survivors; and the self-management perspective.

### **Multidisciplinary approach and coordination of cancer care providers**

The clinical follow-up system as currently applied in survivorship shows low added-value. Multidisciplinary teams often disregard survivorship and rehabilitation issues. The main barriers with regards to their role in undertaking a survivorship care plan is lack of vision regarding redesigning the cancer patients' pathway and the team's workload (94). In addition, multidisciplinary teams also feel that they lack time and information about a follow-up plan. There is little evidence in the literature regarding follow-up care and the role of GPs (see Chapter 6).

The literature shows that survivorship care plans can be built upon the clinical management of a multidisciplinary team and could include addressing patients' late effects of treatment and psychosocial needs with a rehabilitation slant (95–98). Survivorship care plans can be managed according to different models of care coordination with a common starting point of a specialist in a multidisciplinary teams providing follow-up to create a holistic and integrated approach to survivors' health (70,99,100). Three conditions arise as core practices in the literature:

- GPs or a primary care team should play a relevant role in patients' follow-up
- the follow-up model should provide a rapid re-entry to specialized cancer care, if required; and
- a health care professional should assume the role of a coordinating case manager by being a point of reference and contact for the patient and the team.

Other components to be taken into account include the possibility of modifying health insurance coverage to include the follow-up as such and facilitating patient's access to community resources, patients' support groups and volunteers (101).

As 80% of young people with cancer are now surviving, all relevant stakeholders should be informed on possible risks or late effects of the cancer treatment received. The lack of information on many patients' medical history becomes particularly critical as children become adults. The Survivorship Passport initiative (102) can provide a solution to this problematic situation.

### **Education and empowerment of survivors**

Involving patients in prevention, the follow-up and the management of late effects or the rehabilitation process (i.e. access to adapted information on self-management of late effects, on physical activities and dietary rules) is a major challenge. Satisfaction regarding the exchange of information with patients varied greatly among patients with low incomes (103). Online programs and e-health tools currently in development could help to improve the detection and evaluation of needs in supportive and palliative care (104,105). Online search for information, however, was lower for those who had lower education and socioeconomic status. Online programs and e-health may nevertheless offer a good alternative for educating survivors since they are considered cost-efficient and show equal impact with more conventional methods (106,107).

Education programmes are mainly targeted at specific subpopulations (e.g. patients with breast cancer, children, adolescents and young adults) but are also more effective for certain groups (e.g. white and well-educated patients, particularly women) (108).

Many programmes are implemented but not systematically evaluated. Costs and cost-effectiveness are hardly addressed in evaluation studies (109).

### **Self-management**

Cancer survivors are requesting a more active role in their health care. Self-management programmes need to be offered to cancer survivors and provide advices on how to look after themselves after cancer diagnosis, for example with adequate information about potential late effects and their early identification and management (110–115). Health-promoting measures, including web-based programs and telephone counselling, are attractive options to help patient to self-manage.

## Perspectives in survivorship and rehabilitation cancer research

The literature shows that more data are needed concerning the different components of survivorship care. The main unanswered issues are:

- the impact of clinical follow-up on medical outcomes in a wide-range of cancers;
- the clinical, biological and cellular mechanisms of late-effects;
- the impact of supportive care and psychological support on quality of life (short and long term), survival, return-to-work;
- the long-term impact of education programmes;
- the long-term follow-up of adults surviving a childhood cancer,<sup>4</sup> even 10, 20 and 30 years after end of treatment.
- the determinants of cancer inequalities linked to survivorship; and
- the impact and management of comorbidities and other health care disparities.

Furthermore, there is need for research networks and collaboration to initiate innovative clinical trials, such as intervention trials or RCTs.

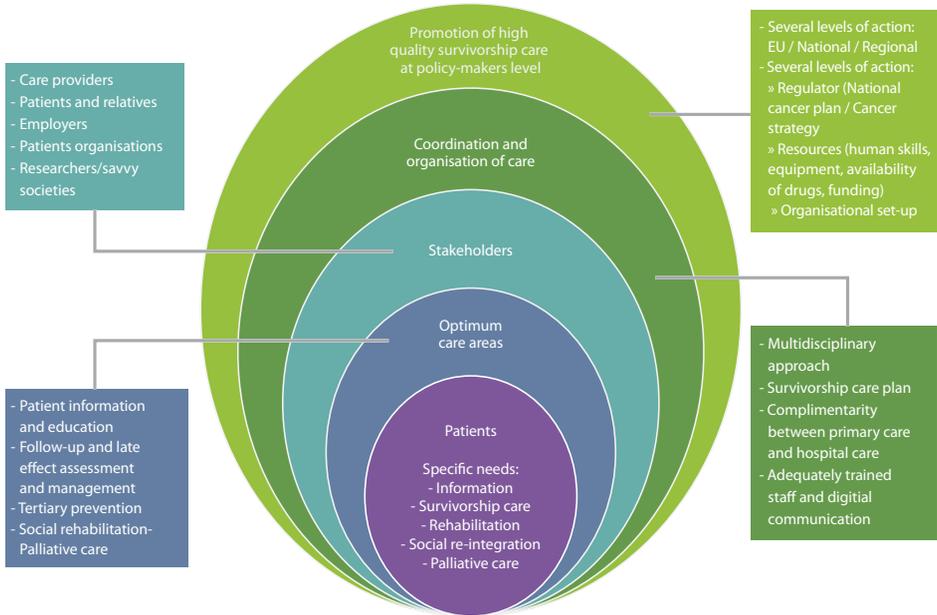
## Conclusions and recommendations

Based on the results obtained, the following section provides policy recommendations regarding three main aspects of the long-term follow-up care plans of cancer survivors: the content, and management and the implementation (Fig. 7.2).

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<sup>4</sup> Several large-scale cohorts of this population have been created in Europe, Canada and the United States. For example, the Childhood Cancer Survivor Study is a multicentre study from the United States for patients treated between 1970 and 1986. This generated the widest quantity of data ever collected on the subject. In France, the L.E.A programme initiated in the early 2000s by two centres, enabled the long-term follow-up of patients (more than 3000) cured from childhood leukemia in 13 oncopaediatric centres.

**Fig. 7.2** Integrated survivorship and rehabilitation care model showing the different components of an effective European organizational survivorship care model with an integrated and personalized approach



### Medical follow-up and tertiary prevention

- An early and personalized follow-up programme should be systematically planned and delivered to each survivor.
- Baseline screening should be performed prior to the start of any cancer-specific treatment. After the first screening regular updates should be performed on an individual basis and followed by adequate provision of psychosocial care.
- An adequate and multidimensional assessment should be made of the survivor’s individual risk of late effects and respective rehabilitation or supportive needs (e.g. physical, psychological, social, cognitive, sexual, nutrition).
- Adequate and updated information on medium- and long-term effects of treatments should be available to survivors, their relatives and to care providers involved in the follow-up.
- In tertiary prevention, self-management should be emphasized, particularly on lifestyle recommendations and on avoiding risks of long-term effects by smoking cessation; weight control and healthy diet, including limited alcohol consumption; sufficient sustained physical activity at every phase of survivorship care; avoidance of excessive exposure to ultraviolet radiation; and stress management.

## Patient-centred approach in long-term survivorship care

- Periodic screening of the physical condition, psychological distress and psychosocial needs should be conducted during the entire cancer pathway and integrated in routine cancer care.
- Rehabilitation and supportive care should be specifically offered to childhood, adolescent and young adult cancer survivors through a routine yearly psychosocial assessment with attention to social, psychological, behavioural and educational and/or vocational issues.
- Social and return-to-work issues should be integrated early into the cancer care pathway. The adaptation of working conditions for any patient returning to his/her previous work should be assessed at early stages.
- Public policies should be developed and implemented to safeguard cancer survivors' working lives, their employability, skills and capacity to work, as well as their motivation to work. Self-employed workers should be offered new skills to help them to achieve balance between health needs and work.

## Management of long-term cancer follow-up care plans

- Psychosocial care, rehabilitation and palliative care should be integrated into the entire cancer pathway, including the survivorship and rehabilitation period. Psychosocial, rehabilitation and palliative care specialists should be members of (or associated with) the medical team in hospitals and in community care.
- The role of GPs and other PCPs should be actively supported to help them to manage all the care plan challenges. Their role should be clearly defined and tailored to the patient and the care plan needs. This role could evolve during the follow-up period.
- Communication between PCPs and health care specialists needs to be improved. Electronic patient records systems should be accessible to all health care providers treating patients. Communication between patients and health care providers needs to be improved.
- A key health care professional assuming a case management role should be assigned to each patient in accordance with medical and/or psychosocial specific requirements. This health care professional could play a main role in reducing the vulnerability of patients, for example with the management of adverse drug effects.
- Transition of care from paediatric oncology to adult medicine should be organized to guarantee adequate long-term follow-up and setting up of appropriate interventions.
- Empowerment of patients and their relatives should be enhanced to increase their participation in self-management, rehabilitation and return-to-work programmes. Online programs would facilitate this process together with the support of patient organizations.
- The use of digital methods (e-health supports) could facilitate sharing of information between patients and care providers and the uptake of the recommendations.

## Perspectives in survivorship and rehabilitation cancer research

- An information and data collection system focused on late adverse effects (physical, psychological, cognitive, social and sexual), coupled with the surveillance of patients and involving PCPs, should be set up. More patient-reported outcome measures and their routine use are needed.
- The use of cancer registries in collecting data on survivors should produce stronger epidemiological data, including lifestyle, quality-of-life or socioeconomic information to better identify the causes of inequalities in survivorship. Moreover, registries should be expanded to additional factors that influence the quality of life (e.g. rehabilitation and employment issues). Patient-reported outcomes could also be a way to collect appropriate information.
- Clinical research should evaluate the feasibility, the efficacy and the cost-effectiveness (including the economical dimension) of non-drug related interventions such as self-management and e-health programs.
- Future research is needed to establish a multidimensional rehabilitation model focused on the quality of life and coordination of complex care to better address the management of late effects across the whole survivorship trajectory. More research would also be required to maximize the long-term follow-up and care of childhood cancer survivors and to identify the genetic risks associated with late effects and second cancers.
- More solid methodological RCTs and cohort studies are needed in order to reduce the intensity of cancer treatments while maintaining their efficacy, thus reducing the probability of late effects, particularly in childhood cancer survivors.

## Implementation

### Improving survivorship and rehabilitation care

- To enhance healthy lifestyles/behaviours in order to improve self-management of late effects with an equity perspective, public policies such as tobacco consumption restrictions, improving access to healthy food and developing actions to facilitate physical activity are needed. Actions targeted to specific vulnerable groups should be developed.
- Professional training and continuous education of health care providers is highly recommended for better information/communication/knowledge of survivorship and rehabilitation needs and management of late effects.
- Adequate financial and human resources should be allocated to the assessment and management of multidimensional late effects and tertiary prevention.
- Systematic screening of distress and physical and psychosocial needs is required for establishing adequate planning and implementation of psychosocial and rehabilitation care. A step-wise or tiered model of psychological care is recommended depending on the level of distress, psychological condition and morbidity of each patient. Interventions can range from basic information (level 1 and 2) to specialized psychological care (levels 3 and 4), as in the United Kingdom NICE guidelines. Interventions can range from:
  - information and psycho-education by primary oncology team to peer support;
  - e-health platforms for psychosocial support and self-management programmes;

- psychological interventions by psycho-oncology trained professionals (e.g. psychologists, social workers, psychiatrists);
  - complementary spiritual support;
  - psychotropic treatments by trained physicians (e.g. psychiatrists, oncologists); and
  - patient support groups
- For the diagnosis of psychological conditions, a specific assessment should be carried out by a psychological care professional: using validated and simple tools and according to clinical practice guidelines for the assessment and management of psychological distress and morbidity and anticipating the specific needs of populations at high risk, including young populations (e.g. children, adolescents, young adults) and relatives.
  - Education and self-management programmes should be developed and evaluated. Assessment of patients' needs should be systematically part of the development of an education programme. The evaluation of these programmes should assess the impact on the personal, organizational and health care policy levels, including cost-effectiveness and impact on health care quality.
  - Professional experts networking on specific late effects (e.g. post-radiation neurotoxicity or drug-related impaired immune function) could facilitate their identification and management and support the GP. Those expert networks could also contribute to improve data collection and research on late effects. GP should contribute to the collection of these data.

### Improving the management of survivorship and rehabilitation care

- Information and communications technology support, such as telemedicine or interoperative patient files, should facilitate patient management and follow-up.
- An information system should be implemented in order to monitor the activity of multidisciplinary teams including multiprofessional involvement, thus enabling the collection of information on process indicators such as coverage (e.g. the number of patients discussed compared with the number of patients under treatment) and implementation of survivorship care plans (e.g. survivorship care plan recommendations effectively implemented).
- Psychosocial and rehabilitation services need to be identified and provided for adequate referral of patients.
- Structural financial resources dedicated to psychological care, rehabilitation and social reintegration services should be embedded in the budgets of national or regional cancer care services. Inequalities of access to these services for underserved populations (e.g. people living in geographical and social isolation) have to be addressed.
- A financing mechanism prioritizing multidisciplinary over monodisciplinary interventions, already existing in some European health systems, can be used to integrate survivorship into the cancer care continuum. Psychological care and rehabilitation resources need to be available and in the private sector needs to be considered eligible for reimbursement from health insurance plans/companies.
- Economic evaluation should be undertaken in order to assess cost-effectiveness of the model of care and inform policy-makers for the most efficient use of resources.

## Ensure the visibility and recognition of survivorship and rehabilitation on the policy agenda

- Health care system and patients benefit from the inclusion of survivorship and rehabilitation issues in national cancer control plans and policies. Partnership development across different professional groups, patients and cancer survivors is beneficial. Enhancing collaboration between the different representatives of these groups to support and optimize work with cancer survivors is advisable.
- It is important to involve patients in advocacy activities for the development of survivorship care, whether they are engaged in a formal organization or not.
- The implementation of a long-term follow-up policy for childhood, adolescent and young adult cancer survivors would improve their QALY, which will have a positive economic impact of reduction of direct (medical care, treatments) and indirect (sick leaves, incapacity of work) costs linked to long-term morbidities in this population. More international and multicentre cooperation could enhance research activities in this area because of the limited number of cases.

## Ensure equal opportunities to all cancer patients

- Opportunities should be created for socially disadvantaged people to fully engage in follow-up programmes.
- Better access to self-management programmes should be available for underserved and deprived populations (low income/low education).
- Public policies should be developed and implemented to support cancer patients from diagnosis to return to work. This would include financial aspects such as access to loans, mortgages and life insurance. Implementation of a pan-European strategy to tackle the differences between workers with cancer in different countries and to prevent discrimination would generate more evidence to better understand the living conditions of cancer survivors who return to work.
- Employers can also play an important role in supporting the survivors' return-to-work process: to explore possibilities of changes in job functions for cancer survivors and encourage them to acquire new skills; to facilitate the implementation of flexible working hours and options (remote working, part-time work); to offer economic benefits to employers who agree to adapt the workplace to the needs of cancer survivors; and to help self-employed workers to adapt their workplace and business to address health needs.
- Patient bills of rights including the right to work with special conditions (e.g. reduced hours of work or adapted working conditions) should be negotiated.

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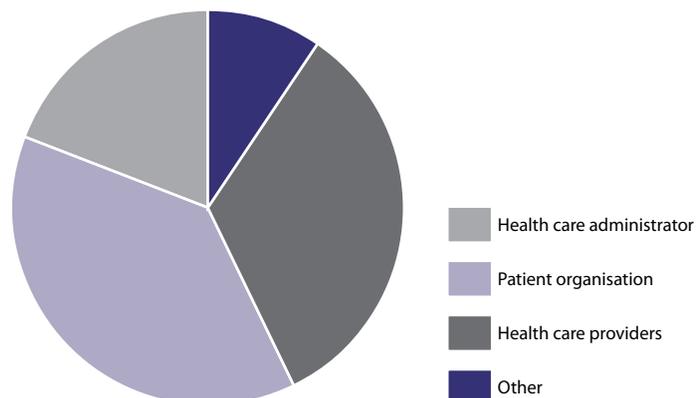
## Annex 7.1. Results of the survivorship care plan survey

### Details on data collected

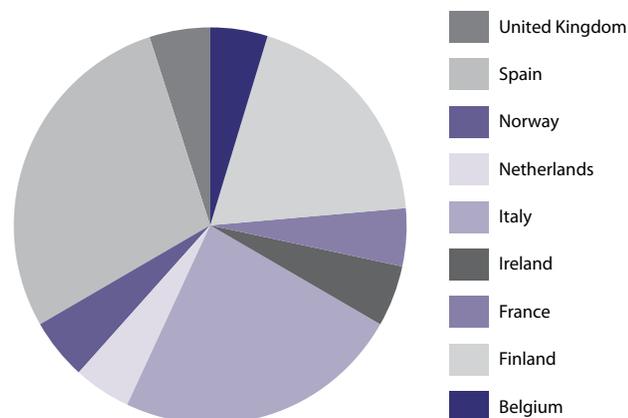
A total of 21 completed questionnaires have been collected. Fig. 7A.1 shows the origins of the data by category and by country.

**Fig. 7A.1** Data collection

#### Origin per category



#### Origin per country



**Note:** A total of 21 questionnaires have been collected.

## Summary of results

Answers varied a lot regarding how patient follow-up is organized and implemented in the EU countries and answers can differ even within the same country. However, all respondents agreed on what is the beginning of the follow-up period: being the period after the acute treatment phase. The length of this period depends on the type of cancer and on the treatment received, for example in Belgium this period lasts for five years and can be up to 10 years in Spain.

According to the results of the survey regarding the role of care providers, the oncologist remains the leader of follow-up care after completion of the treatment. Then in most countries the GP is usually responsible for monitoring the impact of cancer and its treatment on the patient's general health (comorbidities). The role of nurses differed a lot depending on the country, for example care coordinator in Belgium, in France and the United Kingdom, whereas the nurse may just be a contact point in Finland.

During the follow-up period, the identity of the patients, their ages and a record of the treatment(s) received are usually the minimum set of information available to care providers in all countries. In some countries, side-effect information is available (Finland, France Italy, the Netherlands, Spain) as well as rehabilitation care (the Netherlands) or medical history (Finland and Spain). In the majority of countries involved in the survey, supportive care is provided as part of the follow-up, except in Norway and Ireland, and variable in the United Kingdom and Spain. According to the results, pain management and psychological support for patients and their relatives against anxiety and depression are the common grounds for supportive care in EU countries. In addition to these services, symptom and late-effect management, sexuality and fertility support, as well as other supportive care such as nutrition, weight management and beauty care, are offered in a wide range of countries (Belgium, Finland, France, the Netherlands, Spain). Regarding social support and professional rehabilitation, the situation in EU countries is more heterogeneous; only France, Finland and the Netherlands provide services such as social needs evaluation, working ability evaluation and contact details of professionals in this area. In Finland and Spain, these services are only available if the patients ask for them.

The majority of the countries that took part in the survey (76%) claimed that there was no formal survivorship care plan, apart from France, the Netherlands and Finland (only for breast cancer). For patient follow-up, countries often used a mix of tools (paper documents, oral consultations and electronic files) that were commonly shared between all professionals involved with the patient. Only Finland used a nationwide electronic system.

However, 19 respondents out of 21 (two did not answer) thought that a survivorship care plan would be an efficient tool to organize follow-up care. A survivorship care plan, according to respondents, could potentially be an important communication tool between professionals and patients to manage and structure a global follow-up taking into account all aspects of survivorship care.

In addition, 18 respondents out of 21 (two did not answer and one responded "No") thought that a survivorship care plan would be an efficient way to improve quality of care. Not only would it improve the quality of care but it would also improve the access and continuity of care for patients.

Similarly, 18 respondents out of 21 (two did not answer and one responded "No") thought that a survivorship care plan would be an efficient way to better involve PCPs during this period.

Participants to this survey said that there is often no coordination protocol between specialized care and PCPs.

In terms of perceived barriers, the financial one came first (13 respondents), then the technical (9 respondents) and then the professional-related one (8 respondents).

## Survivorship care plan

- A survivorship care plan should be delivered to all patients following a multidimensional needs' assessment and this survivorship care plan should be tailored and updated regularly according to the patient's health conditions.
- After the completion of the acute treatment phase, the patient should be given a survivorship care plan that would contain:
  - baseline information on the personal and medical profile of the patient (identity, age, summary of the treatment received), with additional data on possible late and long-term effects and medical history;
  - a minimum set of tailored supportive care services consisting of pain management and psychological support for patients and their relatives against anxiety and depression
  - possibly also healthy lifestyle issues, including for example tobacco cessation, physical activities, nutrition and weight management, beauty care, as well as sexuality and fertility support; and
  - social support and professional rehabilitation services.
- The survivorship care plan should be elaborated and implemented by the multidisciplinary team composed of:
  - an oncologist in collaboration with other professionals to plan the follow-up process;
  - a GP who deals with the impact of cancer and its treatment of the general health;
  - a (specialist) nurse or a support worker who is in charge of coordinating follow-up care among all services providers involved; and
  - a community care centre, which deliver information, educational activities about survivorship care.
- From a technical point of view, in order to meet its communication and care coordination objectives, the survivorship care plan should be:
  - accessible to all health care professionals having therapeutic relationships with the patient;
  - updated regularly; and
  - use a format that optimizes the understanding and the communication of information between patients and health care providers (and among health care providers).

## Advice for implementation

Treatment Summary and Survivorship Care Plan from the American Society of Clinical Oncology or the National Comprehensive Cancer Network survivorship guidelines are good examples.

- Engage financial and professional resources.
- Ensure availability of dedicated resources for multidimensional cancer rehabilitation services.
- Appoint a patient navigator to guide the patient through existing rehabilitation resources.
- Evaluate the implementation (patient-reported outcome measures) and outcomes of the survivorship care plan.

## **Annex 7.2 Assessment of patient's symptoms and needs and the orientation to adequate intervention in psychological supportive care**

The literature review showed that early and systematic detection of needs in psychological support, social rehabilitation (in particular for return-to-work issues), physical rehabilitation, supportive and palliative care is necessary in order to orientate patients towards tailored health care interventions. It also demonstrated the necessity to anticipate certain issues that the patients and their relatives will face during the survivorship and rehabilitation period.

In this context, one of the objectives of Chapter 7 was to set the basis of a common European process that would enable the assessment of patients' symptoms and needs in order to facilitate their guidance towards tailored interventions in supportive care. The process is presented via several questions that reveal the modalities of implementation.

### **Why?**

The purpose of a qualitative assessment of symptoms and needs in cancer settings is about:

- improving the quality of health care (targeting each patient's needs and directing resources to optimize patient's clinical outcomes);
- improving clinician–patient communication; and
- regularly monitoring physical, social and psychological functioning to better address these needs.

The qualitative assessment of symptoms and psychosocial needs is not only useful for the orientation towards adequate care interventions but also for the patients themselves, who increasingly express their interest of being involved in their supportive care pathway.

### **When?**

Symptoms and needs must be assessed as early as possible and at every “step” of the cancer journey: diagnosis, treatment, rehabilitation, follow-up and end of life.

### **Who?**

The qualitative assessment of symptoms and needs should apply to all cancer patients and survivors. Health care professionals should incorporate the detection of patient-reported outcomes in their routine clinical activity.

### **What?**

Qualitative assessment of symptoms and needs should cover:

- physical aspects (functional assessment and symptom burden)
- social aspects (family, relational, employment issues)
- psychological aspects (emotional, spiritual, sexual)
- perceived barriers to care
- satisfaction with cancer care.

## How to assess?

Tools and measures should be defined at a local level, but they should share common characteristics agreed at the European level. They should be:

- very brief;
- validated in the local language (patient's language); and
- good performance parameters: validity, reliability, sensitivity, specificity, positive predictive value.

The literature emphasizes that tools should be accepted and shared by the front-line staff that will be using them in order to enhance the collaboration.

The qualitative assessment of symptoms and needs can be performed with traditional tools (paper and pencil tests) but also with the more recent digital tools, which have some limitations but also promising opportunities.

Personal interactions between health professionals and patients remain crucial to the process of obtaining valuable, reliable and viable information by which to initiate appropriate biomedical and/or psychosocial treatment.

## Final objective

Every European cancer patient and survivor should have an assessment of symptoms and psychosocial needs that should be incorporated into the formal patient record system.



