

In recent years, the European Union has taken action to support national preparation of a structured document to define all the services and actions related to cancer control. These documents are most often referred to as National Cancer Plans or National Cancer Control Programmes. By 2013, almost all EU member states had already adopted some form of National Cancer Plan, thus structuring their commitment and resources to cancer control.

In the framework of the EU co-funded project Joint Action EPAAC, one of the activities was dedicated to the production of a document that would serve as a guide to member states in shaping their future cancer planning or/and cancer control activities. The result of these efforts is the present document, which we hope will be a living document in line with the needs of all member states and the EU as a whole.

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# European Guide for Quality National Cancer Control Programmes

Editors:

**Tit Albreht, Jose M. Martin-Moreno,  
Marjetka Jelenc, Lydia Gorgojo, Meggan Harris**

ISBN 978-961-6911-60-3



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Co-funded by  
the Health Programme  
of the European Union

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Publisher:

National Institute of Public Health, Trubarjeva 2, 1000 Ljubljana, Slovenia

Email: [info@nijz.si](mailto:info@nijz.si)

[www.nijz.si](http://www.nijz.si)

Ljubljana, 2015

ISBN 978-961-6911-60-3 (pdf)

Typesetting: Luka Pajntar, [kaloop.si](http://kaloop.si)

Printed and bound in Slovenia by Grafika 3000

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Number of Copies: 500

Price: 0,00 EUR

This publication arises from the European Partnership for Action Against Cancer, which has received funding from the European Union through the Consumers, Health, Agriculture and Food Executive Agency of the European Commission, in the framework of the Health Programme 2008-2013. The European Commission is not responsible for the content of this publication. The sole responsibility for the publication lies with the authors, and the Executive Agency is not responsible for any use that may be made of the information contained herein.

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CIP – Cataloguing in Publication

National and University Library, Ljubljana, Slovenia

616-006(082)(0.034.2)

EUROPEAN guide for quality national cancer control programmes / editors Tit Albreht ... [et al.]. - El. book. - Ljubljana : National Institute of Public Health, 2015

ISBN 978-961-6911-60-3 (pdf)

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279946240

# Executive Summary

*Jose M. Martin-Moreno*

A key output of the European Partnership Action Against Cancer (EPAAC), this report summarises the technical components of an effective and high-quality National Cancer Control Programmes (NCCPs). The report is directed towards policymakers and health system administrators who wish to develop, implement or improve their NCCP, taking into consideration the main vertical and horizontal areas for policy action. Three parts (Cancer prevention, Integrated care, and Supportive functions within the health system), are divided into 10 chapters, covering the following topics:

## **Part I – Cancer Prevention**

### **Chapter 1. Primary prevention and health promotion**

The first section has to do with planning, explaining the basics of assessing cancer risk in a given population, prioritising preventive actions, and setting realistic objectives whose achievement can be measured and monitored. The next section describes programme elements at three levels: regulatory, community and healthcare. Potential programme components are included in a bullet point list for consideration. Finally, and as with all chapters of this report, a series of structural, process and outcomes indicators are proposed to help managers monitor progress towards their specific objectives.

### **Chapter 2. Cancer screening and early detection**

This chapter begins by citing the main European guidelines for population-based cancer screening for breast, cervical and colorectal cancer, which constitute the main technical guidelines for such programmes. However, a few key areas are summarised here for NCCP decision-makers at a macro level.

The planning section sheds light on how to assess the feasibility of a screening programme based on evidence, as well as how to prioritise services and population groups and set targets. A further section related to planning focuses specifically on programme implementation, covering aspects such as coordination, development of an action plan, implementation of additional technical tools, and sustainability. Next, programme elements are discussed, including the definition of a target population, service performance, clinical follow-up and treatment, and quality control. These elements should be evaluated using the indicators at the end of the chapter.

## **Part II. Integrated care**

### **Diagnosis and treatment**

Integrated care begins with diagnosis, following on to treatment. As this is by far the most expensive component of an NCCP, a full situational analysis, using data on outcomes as well as health system indicators data, is necessary before specific priorities for action can be decided. Once these have been established, decision-makers can consider different measures to improve diagnosis (such as fast-track systems, limitations on wait times, or investments in diagnostic resources) and treatment. Apart from specific recommendations on the development of clinical practice guidelines, measures are considered in the areas of surgery, medical oncology, radiation therapy, paediatric oncology and rare tumours. Finally, the health services organisational aspect is considered, touching on the need to create and maintain multi-disciplinary teams, networks for specialist collaboration, and surveillance following cancer treatment. Finally, just before the section on indicators, some reflections and recommendations on strengthening the role of the patient are described.

### **Psychosocial oncology care**

Improvement in clinical outcomes goes hand in hand with maintaining a good quality of life for patients. For this to happen, proper attention must be paid to supportive care, including psycho-oncology. This chapter discusses the necessary programme elements in this area, which include enhanced communication training for professionals working in cancer care, incorporation of screening for distress into patient visits, evidence-based psychosocial interventions, and the inclusion of these services as an integral part of a multi-disciplinary team.

### **Survivorship and rehabilitation**

As survival outcomes improve, the population of cancer survivors will only grow. This collective faces specific problems that combine physical rehabilitation needs with long-term psychosocial needs and behavioural modifications. NCCPs should be informed by a specific needs assessment study to understand the population of cancer survivors in their country. Once specific goals and priorities have been established according to age groups and cancers, programmes can be implemented in the following areas: patient-centred rehabilitation programmes, social support for patients and families, and self-management programmes.

### **Palliative and end-of-life care**

Unfortunately, many patients will suffer from debilitating pain, and not all will survive their cancer, thus it is important to incorporate palliative care early on in the care process and continue to provide services to patients and their families throughout disease progression and even after death. General planning aspects are discussed (risk assessment, prioritisation and goal-setting), before the principle organisational issues are described. These include service organisation, resources, quality assurance, policy provisions, financing, training, monitoring and evaluation, and investments in research. Finally, a list of indicators is proposed.

## **Part III. Supportive functions within the health system**

### **Governance and financing**

This chapter heads off the guide's section on horizontal issues necessary for NCCP implementation, and its placement at the start of the section is intended to highlight the importance of strong leadership and careful management of the programme. It discusses general principles on managing, planning and monitoring cancer services performance, and also discusses institutional structures that favour success, including the need to designate an NCCP coordinator and to set specific resources aside for managing implementation. It also touches on issues related to knowledge management, sustainability and financing.

**Cancer resources**

This chapter discusses the specific resource considerations that should be integrated into the NCCP. Resources can fall into several categories: human, infrastructure, health technology, and cancer-specific expenditure. Availability of resources must be matched with the goals set in vertical programme areas, with specific measures to build up future capacity where needed.

**Cancer data and information**

A high quality cancer registry is absolutely essential to understanding population needs and health system performance, and so it constitutes a cornerstone of any effective NCCP. This chapter discusses registries and other data sources (population data, other disease registries, healthcare audits, etc.), making recommendations on optimising interconnectivity in order to understand all the dimensions of cancer epidemiology and care. Organisational considerations are also taken into account, including the population to be covered, the necessary legal provisions that must be in place, methods of registration, and linkages with other sources. Specific outputs (indicators to gather) are also listed, along with a series of indicators on the quality of the cancer registries themselves.

**Research**

Finally, cancer research is considered from a health policy perspective, with specific recommendations on how to develop and implement a national cancer research agenda. This should begin by first trying to untangle the current research activity being undertaken by a variety of different actors, and then developing priorities according to cancer burden and other criteria. A proper regulatory framework should also be established, considering both the national and international level. Once these pieces are in place, health systems can better decide where to invest their research funding. Throughout, patient participation should also be sought, in both the planning stages (when priorities are being set) and in the performance of the research itself (increasing access to clinical trials).

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# Preface

*Tit Albrecht*

The European Union has in recent years taken action to support national preparation of a structured document to define all the services and actions related to cancer control. These documents are most often referred to as National Cancer Plans or National Cancer Control Programmes.

In 2009, when launching the European Partnership for Action Against Cancer (EPAAC), the European Commission decided to call upon the Member States to set up National Cancer Plans or Strategies by the end of 2013. The mentioned partnership was supported by a project co-funded by the European Commission, called the EPAAC Joint Action. One of its Work Packages was entirely dedicated to the topic of National Cancer Plans. All Member States were surveyed with the purpose of informing the EU policymakers about the extent to which the target of 2013 will have been achieved and exploring the contents of their respective plans with the objective of developing a European Guide for their preparation. Six Member States – Belgium, Ireland, Italy, Malta, the Netherlands and Slovenia – together with two international experts, Prof Jose M. Martin-Moreno and Dr Lydia Gorgojo, dedicated extra time to produce the present Guide. It should be seen exactly as it name implies – as a guide on what contents should be ideally present in the guide and what particular aspects of cancer management and control require special attention of policymakers. This is particularly important when such an important policy mid-term document is prepared for adoption at a high national policy level. It is intended for all those who are involved in preparing such documents and for all those that need to be informed about the contents and importance of the different activities, actions and services in cancer control.

# Introduction

*Jose M. Martin-Moreno, Lydia Gorgojo*

Since the World Health Organisation first published its *National Cancer Control Programmes: Policies and Managerial Guidelines* (1) in 2002, the role of these plans in national cancer policy has grown tremendously, particularly in Europe. Whereas only three Member States of the European Union had implemented a National Cancer Control Programme (NCCP) in 2002, virtually all EU countries have taken decisive steps in this direction now, in part thanks to the leadership of EU-led initiatives such as the European Partnership for Action Against Cancer (EPAAC) (2).

At their core, NCCPs aim to improve cancer control through better planning and coordination of the range of cancer services offered through the national health system, from prevention and health promotion to rehabilitation and palliative care services. This complex task requires action at all levels of the health system and beyond, including aspects related to:

- Leadership and vision;
- Policy development and management;
- Financing, resource generation and allocation;
- Coordination of health and social services;
- Social participation, including patient participation;
- Better use of scientific evidence; and
- Monitoring, evaluation and oversight.

The past decade in Europe has served as a breeding ground for innovative policy approaches to NCCPs, wherein each country has attempted to adapt the main principles (quality, cost-effectiveness, equity and accessibility) to its own national context. These circumstances have given rise to a plethora of organisational and financing models, which provide great opportunities for benchmarking, analysis and mutual learning.

## **Aims of this guide**

EPAAC included among its main aims the support of EU Member States in their pursuit of developing or improving an NCCP. Early work within this Joint Action focused on characterising the state of the art in NCCPs in the EU, engaging Member States in a survey exercise meant to gather information as well as spur discussion and debate over what essential elements an NCCP should include.

The present guide springs from this experience, and has several aims:

- To provide a synthesized description of the broad range of cancer control services that may be offered through national health systems;
- To propose a list of indicators that countries may consider in order to improve the monitoring and evaluation of their plans;
- To promote some convergence in national approaches to NCCP planning, with the ultimate aims of:
  - a. Fostering the ability of policy analysts to compare plans within and across European borders; and
  - b. Supporting a common understanding of cancer planning among EU policymakers, which will in turn facilitate collaboration across borders.

## **Notes on using this guide**

The information contained in this document is by no means exhaustive, nor is it meant to constitute a single, authoritative guide to programme planning. Rather, it is meant to serve as a concise outline for policymakers who wish to understand the basics of cancer control policy. Additional sources with detailed information have been provided where relevant.

It should also be noted that the group of programme elements described in this guide is not meant to be considered for implementation as a whole. National policies must necessarily be adapted to national health system organisation, specific priorities and resource availability.

The list of proposed indicators has been compiled as a concrete means to increase the comparability of EU cancer plans, both within countries (to analyse time trends) and between EU Member States. Although national health systems vary widely in terms of resources and service organisation (and all comparisons will need to consider problematic issues hindering straightforward cross-country analyses), we believe there is considerable scientific value in being able to compare specific indicators from different countries. This kind of research supports the rights of Europeans to equal access to health services (articulated in Directive 2011/24/EU on patients' rights in cross-border



healthcare), and it also helps to identify best practice for planners across the continent. These advantages are present despite the inevitable shortcomings of comparative analyses between European NCCPs, and, we believe, constitute the main justification and utility for this guide.

Finally, conscious of the potential shortcomings of this guide, we would like to encourage Member States, partners, patient associations, the scientific community and cancer control advocates throughout the European Union to periodically make proposals to improve this text, which should be considered a living document. The collective—and evolving—experience and expertise from around the EU is, we believe, the most valuable asset in advancing in this noble endeavour.

# Acknowledgements

We would like to begin by thanking all the authors for their hard work and enthusiasm they have brought to the topic National Cancer Control Programmes.

In addition, we would like to thank the reviewers, some of them EPAAC JA work package leaders, Ahti Anttila, Milena Sant, Wendy Tse Yared, Julio Celis, Camilla Amatti, as well as Anna Rouillard, Ingrid van den Neucker, Victoria Hedley, Kate Bushby, Renee Otter and Lawrence Von Karsa.

For the constructive comments we would like to thank Institut National du Cancer (INCa, France), German Ministry of Health, Italian Ministry of Health, Centre for Public Health Research in Valencia, Spain and participants in the working meeting of the EPAAC Steering Committee.

We would like to thank our colleague at the Slovenian Institute of Public Health Aleš Lamut for his technical support.

Finally, we would like to thank European Commission who has made EPAAC Joint Action possible.

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Part I.

# **Cancer Prevention**



# Primary Prevention & Health Promotion

*Regine Kiasuwa, Marc Van den Bulcke*

## Background

Cancer often results from the complex interaction of cancer-causing agents from the environment in addition to genetic factors. The impact of many of these factors can be mitigated through health promotion and disease prevention focused on healthy public policies, the creation of supportive environments, the strengthening of community actions, the development of personal skills and the reorientation of health services (3, 4). For optimal effectiveness throughout the population, actions should consider available evidence and maintain a focus on equity.

After assessing cancer risk within the population, health planners should prioritise action in the following areas: national health protection regulations and legislation, community health promotion tackling determinants of diseases through a whole-of-society approach, and preventive services within the health system.

## 1. Planning: risk assessment, prioritisation and goal setting

### Cancer risk assessment

Before commencing a new programme for cancer prevention, baseline measurements for the main risk factors need to be established. These data should be disaggregated according to population groups (socioeconomic, geographic, sex, age, ethnicity and educational level) in order to identify the groups at

highest risk. The most important modifiable risk factors are primarily related to behaviour, and include:

- Tobacco prevalence;
- Alcohol intake patterns;
- Diet;
- Physical inactivity, and
- Obesity.

Other risk factors include:

- HBV prevalence;
- HPV prevalence;
- Exposure to environmental carcinogens in the air, water and food;
- Exposure to occupational carcinogens.

See chapter 9 on cancer data for information on the appropriate surveillance mechanisms which should be in place to track these indicators.

### **Prioritisation of prevention actions**

To optimally use available resources, priorities will have to be set among the identified risk factors and the target-groups through:

- The establishment of a focal contact point (to coordinate the activities);
- A clear description of the applied methodology and criteria to rank risk factors and to identify target populations;
- An audit of other health system activities that target the same risk factors, in order to avoid duplication and seek synergies. This is particularly relevant for the four main behavioural risk factors (smoking, alcohol, diet and physical inactivity), which are also extremely relevant in the control of other non-communicable diseases (NCDs). Therefore they need to be in the centre of comprehensive prevention and health promotion communications strategies;
- The careful selection and prioritisation of risk factors and associated interventions according to the local context.

### **Setting objectives**

The SMART principles (Specific, Measurable, Attainable, Realistic, and Time-Based) for setting NCCP objectives in prevention, as in other areas, are a useful guideline for planners. Actions should specifically target high-risk groups in order to make the most impact and favour health equity. They should also be aligned with the availability of human, financial and technological resources (see chapter 8 on Resources).



## 2. Programme elements

### National policy-setting, including legislation and regulations

National policies and legislation should support and reinforce health services offered in the community and in health centres, providing a coherent framework that establishes cancer prevention as a national objective, not one limited to the health sector. Prevention efforts will depend on the capacity of the central or regional Ministry of Health in leading and coordinating broad, inter-sectoral efforts in community health promotion. Partners in this whole-of-society endeavour should include local stakeholders, including educators, NGOs, patient advocacy groups, local government, law enforcement, health providers, religious leaders, community activists and businesses, among others. Specific efforts will be necessary to engage vulnerable communities, including groups with lower socioeconomic status, in order to address health disparities. Finally, relevant initiatives at an international and EU level should be identified and analysed for possible areas of synergy and collaboration.

- National policy should include respective strategies to tackle the main shared behavioural risk factors for NCDs, including:
- A national tobacco control strategy, in line with the Framework Convention on Tobacco Control (5);
- A national alcohol strategy and/or public health laws, in line with the WHO global strategy to reduce the harmful use of alcohol (6);
- A national strategy promoting a healthy diet and regular physical activity, in line with the WHO global strategy (7) and/or the EU strategy on nutrition, overweight and obesity-related health issues (8).

In addition, cancer prevention should be fostered through other, centrally directed public health actions:

- Establishment of occupational safety framework, to increase awareness, detection and monitoring of cancer risk in the workplace;
- Environmental and health protection laws safeguarding water and air quality (including to reduce exposure to second-hand smoke);
- Bans on sunbed use for minors;
- Ban on use of asbestos;
- A health impact analysis in all other national policymaking spheres, with cross-checking of potential health effects against national health priorities;
- A national research agenda on health promotion and disease prevention.

## Community health promotion

The broad policies outlined above should also work to support Ministries of Health in leading intersectoral actions in health promotion\* in the following areas:

### *Creating supportive environments*

- Strict enforcement of national legislation and regulations concerning smoke-free laws, workplace safety, alcohol use and others;
- Increased availability of facilities/green space to perform physical activity;
- Increased availability and affordability of fruits and vegetables, especially in underserved areas;
- Social networking approach (through online social media, but also through local community networks) to tackle societal norms that condone high-risk health behaviour.

### *Strengthening community actions*

- Preventive campaigns in cooperation with businesses, factories and labour unions to reduce the risk of occupational exposure to carcinogens;
- Improved identification of work-related cancers through better reporting and monitoring systems;
- Pedestrian and bicycle-friendly urban development.

### *Development of personal skills*

- Celebration of events that give visibility to cancer prevention, such as World No Tobacco Day, the European Week Against Cancer, World Cancer Day, Breast Cancer Awareness Month, etc.;
- Life skills-based health promotion programmes/seminars in schools, workplaces and for local and regional government officials;
- Dissemination of the European Code Against Cancer in schools, workplaces, health and community centres (9);
- Communication campaigns, adapted to different media and audiences, to raise awareness of different risk factors for cancer (smoking, alcohol, diet, physical inactivity, UV rays, carcinogens in the home or workplace). When relevant, cancer-related messages should complement other disease prevention messages.

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\* Although disease prevention and health promotion often share goals, they can be conceptually divided into two groups of actions: disease prevention efforts are generally concentrated within the health system (particularly in primary care), while health promotion relies on intersectoral actions and tackles broader determinants of health (including social determinants).

### **Preventive services within the healthcare system portfolio**

Finally, the role of the healthcare centre and the primary care physician is irreplaceable in cancer prevention efforts. Depending on resource availability and health system capacity, primary preventive services within the healthcare system may include the following:

- Immunisation against HBV, HPV;
- Protocols and worker incentives in primary and specialised care to increase personalised health counselling to prevent cancer and other NCDs. Specific time should be periodically allocated for lengthier appointments, in which the GP or specialist can conduct a health interview on environmental and genetic risks;
- Special protocols to monitor patients with a higher risk for cancer, including those that present behavioural risk factors as well as those with comorbidities that increase cancer risk (HIV, Hepatitis B and C, Helicobacter pylori infection, HPV);
- Addiction treatment or prevention services to tackle tobacco and alcohol use;
- Genetic screening for patients with a family history of cancer (10).

### **3. Indicators**

Three types of indicators can help policymakers monitor the implementation and effectiveness of cancer prevention strategies: structure (including legal framework), process and outcome.

Types of indicators	Core	Additional/ Supplementary
Structure	<ul style="list-style-type: none"> <li>• Existence of a cancer prevention working group to coordinate action and implementation with other areas of the health system and government</li> <li>• Implementation of the Framework Convention on Tobacco Control</li> <li>• Existence of a food and nutrition framework strategy</li> <li>• Existence of a strategy to promote physical activity</li> <li>• Existence of a national strategy document to limit alcohol-related harm</li> <li>• Existence of an occupational safety framework with national reporting mechanisms on safety related to the exposure to carcinogens on workplace</li> <li>• Inclusion of HPV and HBV vaccines in the immunisation calendar</li> <li>• Allocation of money to fund specific actions, including explicit allocations for cancer epidemiology and public health research</li> </ul>	<ul style="list-style-type: none"> <li>• Existence of legislation banning sunbed use among minors</li> <li>• Number and distribution of affordable exercise facilities per population, with a special emphasis on increasing their presence in underserved areas</li> <li>• Revision of clinical protocols for primary and specialised care, to increase focus on prevention</li> <li>• Existence of strategic aids to educators, businesses and industries to help these stakeholders prevent cancer in their settings</li> </ul>
Process	<ul style="list-style-type: none"> <li>• Audit reports on enforcement of health protection legislation</li> <li>• Number of interventions to treat tobacco or alcohol dependence</li> <li>• Immunisation coverage for HPV and HBV</li> </ul>	<ul style="list-style-type: none"> <li>• Number of publications and communication materials (especially the European Code Against Cancer) distributed to health and community centres</li> </ul>
Outcome	<ul style="list-style-type: none"> <li>• Cancer incidence and mortality rates, trends and projections*</li> <li>• Prevalence of tobacco use among adults, young people (10–14 years old), and ex-smokers*</li> <li>• Consumption of alcohol*, disaggregated by sub-populations</li> <li>• Attitudes towards physical activity*</li> <li>• Consumption per capita of fruits and vegetables*</li> <li>• BMI distribution in the population*</li> <li>• Prevalence of occupational exposure to carcinogens*</li> <li>• Exposure to asbestos: mesothelioma incidence and mortality trends*</li> <li>• Prevalence of use of HRT drugs*</li> </ul>	<ul style="list-style-type: none"> <li>• Protection against excessive UV exposure</li> </ul>

\* EUROCHIP indicator

# Cancer screening and early detection

*Regine Kiasuwa, Marc Van den Bulcke, Marc Arbyn, Renee Otter*

## 1. Background

Population-based cancer screening programmes have proven effective in reducing the incidence or improving the prognosis of three common cancers: cervical, breast and colorectal. While screening procedures exist for some other sites, including prostate and lung cancers, more scientific evidence is required before these procedures meet basic effectiveness and cost-utility criteria.

The EU council Recommendation on cancer screening (2003/878/EC) lays out the basic principles of population-based cancer screening, and each of these will need to be taken into account during programme planning (11). Moreover, detailed guidelines on quality assurance for population-based screening programmes for breast (12), cervical (13) and colorectal (14) cancer have been published by the European Commission and the Directorate-General for Health and Consumers, in conjunction with the International Agency for Research on Cancer (IARC). In addition, the Commission is leading efforts to set up a voluntary quality assurance scheme for breast cancer and to update the 2006 guidelines. These instruments should constitute the main operational aid to health systems wishing to implement or improve their screening programmes. This section will summarise the main points contained in these comprehensive documents.

## 2. Planning: feasibility, prioritisation and goal-setting

In view of the complexity and resource requirements associated with appropriate secondary cancer prevention programmes, it is particularly important to investigate their feasibility prior to inclusion in an NCCP.

### Establishing programme feasibility based on evidence

Ten conditions should be met before considering implementation of a screening programme (15):

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

Certain considerations should also be taken into account before deciding that there is enough evidence to embark in screening programmes. Certain biases are associated with any screening programme, and if not taken into account in observational studies, they may significantly skew conclusions on programme effectiveness. The gold standard for assessing efficacy remains randomised clinical trials, with specific mortality or incidence indicators as outcomes.

- *Lead time bias.* Detecting a cancer early may lead to a longer perception of survival, even if the course of the disease is not altered;
- *Length bias.* Screening is more likely to detect slow-growing lesions/tumours rather than the more dangerous kinds of lesions that have a shorter asymptomatic period. This point is particularly important, for instance, in the case of prostate cancer, which may be detected early without reporting any benefits to the patient;
- *Selection bias.* This refers to factors that differ between those willing to get tested and those who are not and which distort the assessment;

- *Overdiagnosis.* Screening may detect harmless abnormalities that would not affect the patient's life if left untreated. This may lead to painful, distressful interventions that use health system resources needlessly.

In short, the ultimate goal of screening is to reduce morbidity or mortality from the disease by detecting diseases in their earliest stages, when treatment is usually more successful, and this should be evidence-based.

## Prioritisation

A national population-based cancer registry, or a series of interconnected regional cancer registries, is crucial to effective planning of screening programmes. If cancer registration does not exist, it must be established early in the process of quality assured screening programme implementation. The data that registries provide will help planners to better understand the cancer burden—which cancers amenable to screening are most frequent, where they occur and in what sub-populations (rural vs. urban, between socioeconomic groups, etc.).

Based on this information, screening programmes should be designed keeping in mind the following criteria:

- *Cost-effectiveness.* The cost-effectiveness of any given screening programme will depend on a number of context-specific factors, so it is important that each programme is continuously evaluated with the aim of both improving patient outcomes and using resources as efficiently as possible. Age groups that are at the highest relative risk for a particular cancer should receive priority in terms of resource allocation, while broader age ranges should be targeted according to a risk-benefit analysis and the availability of resources (see table 1 for a summary of European recommendations);
- *Resources.* Most countries have at least some resources available for screening, including specialised and administrative personnel, diagnostic equipment, and laboratories. Scaling up screening programmes must be a stepwise process, optimising the human, physical, technical and financial resources already available while simultaneously building capacity before the next phase of implementation begins;
- *Equity.* It is well-known that opportunistic screening is more likely to widen gaps in health inequities, but even population-based programmes may favour the participation of groups with a higher socioeconomic status (16), although this is not always true (17). This fact should be taken into account and addressed with specific measures aimed at increasing the participation of groups at higher risk;
- *Availability of treatment services.* Logically, a fully implemented, population-based screening programme is of limited value if health services are

not available to treat the detected lesions, so screening programme capacity must be roughly in line with capacity for health services related to a positive diagnosis.

**Table 1.** Summary of European recommendations for cancer screening: methods, target population and screening interval\*.

Cancer	Method	Target population	Screening interval
1. Cervical	Cytology	Women aged from 25–30 up to 60–65 years	3–5 years
2. Colorectal	Guaiac or immunochemical FOBT	In the age group 50–74 years, for all adults (women and men)†	2 years
3. Breast	Mammography	Women aged 50–69	2 years

Adapted from (11–14)

\*Note: Future revisions of these recommendations should be taken into account, keeping pace with subsequent editions of evidence-based recommendations on cancer screening in the EU. For example, HPV primary testing for cervical cancer screening, flexible sigmoidoscopy screening for bowel cancer; screening and changes in the recommended age ranges for any screening may be expected in the near future.

† The indicated age range for colorectal cancer is to be understood as maximum range; subject to national epidemiological evidence and prioritisation, smaller age ranges may be appropriate.

**Goal-setting**

Once the baseline figures are established based on data from cancer registries and screening facilities, and the availability of resources has been audited for feasibility of programme implementation or expansion, specific and realistic goals should be set for structural, process and outcome indicators (see below) during the NCCP time period. This tiered method will allow programme managers to monitor roll-out and operation in addition to outcomes.

**3. Planning quality-assured programme implementation**

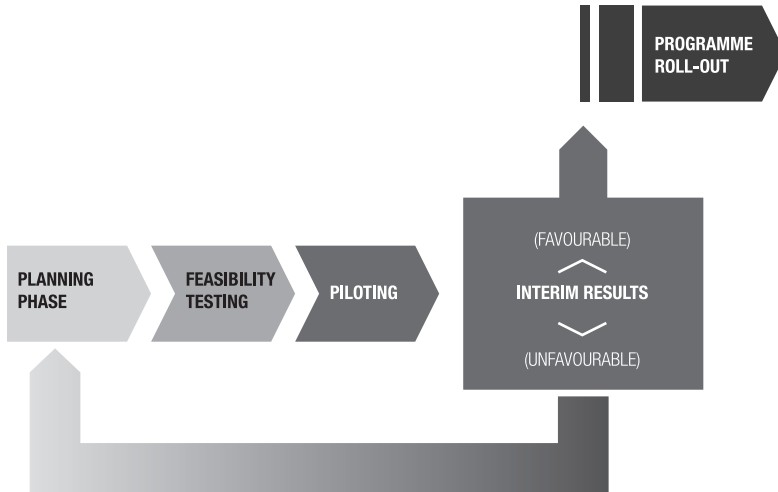
**Coordination**

Once policymakers have made the decision to establish a population-based cancer screening programme, a competent, autonomous programme coordinator



should receive the mandate to manage the entire implementation process. (Figure 1)

**Figure 1.** Population-based cancer screening implementation process.



The coordinator should be provided with sufficient organisational and financial resources to effectively manage the screening programme and take further decisions as necessary. These decisions should enable the coordination team to establish the screening programme in the respective health services context, taking into account the need for the professional and organisational management to control the quality of the entire screening process, including informing and inviting the target population, performance of the screening test, diagnosis, therapy and subsequent care (18–22).

### Action plan

One of the first tasks of the coordinator will be to develop an action plan (22) to assure the entire process of programme implementation, taking into account the points mentioned below, in the section “Programme elements”. Specific actions will need to be paired with resources (human, technological and financial), and if these are lacking, the plan will need to include actions to close those gaps. Likewise, accountability mechanisms, supported by measurable indicators, should accompany each phase of the plan.

### Additional tools

The programme coordinator should develop the additional tools essential to quality assured management of the programme including:

- Computerized information systems and accessible registries (e.g. for call and re-call systems and fail-safe procedures in follow-up of participants with abnormal test results);
- Sustainable technical capacity for recording and monitoring key performance and quality indicators of the screening process, and for analysing the results and feeding them into quality management processes.

### **Assuring sustainability**

- **Active, long-term government commitment** is essential to provide the necessary sustainable resources to gradually establish the screening service and to tailor expansion of the programme to the capacity of the health care system;
- **Benchmarks for sustainable financial support** (budget targets and coverage targets) should be established early in the planning phase and their achievement should be monitored by an independent organisation experienced in the field;
- **Investment in quality assurance** should also be monitored and regularly compared to the level recommended in the European quality assurance guidelines (10–20 % of programme expenditure; more in the start-up phase) (22), and reported to the public.

## **3. Programme elements**

Once the conditions above are met, programmes should be planned to cover four main aspects: the population component, test execution, the clinical component and quality control.

### **Population component: Definition/identification of target population and recruitment**

Uptake (i.e., the proportion of screening invitees in a given year for whom a screening test result is recorded) is the most important factor in determining the success of a screening programme.

Effective recruitment for screening programmes has three steps:

- Creation and maintenance of a detailed database for the target population, including name, age, sex, contact information, healthcare identification number, and mechanisms to consider any potential exclusion criteria (recent screening, positive diagnosis, etc.);

- Personal, written invitation, with verifiable individual record by dedicated programme services;
- Removal or mitigation of barriers to screening, making screening procedure free and as convenient as possible;
- In parallel, screening programme managers may coordinate with health promotion campaigns to optimise the focus on cancer prevention, including through the use of existing national or European tools, such as the European Code Against Cancer (9).

### **Service performance**

The choice of screening method and recommended screening interval are key primary considerations. As per the European recommendations outlined in table 1, conventional cytology, mammography and FOBT currently present the strongest evidence for efficacy and cost-effectiveness, although it should be noted this is an active area of health technology research, so recommendations are subject to periodic revision. The ideal screening interval depends on the sensitivity of the testing method as well as the latent period of a potential malignancy, so the intervals detailed in the table may not be valid for other possible methods, for example colonoscopy.

These variables should be discussed with patients before any procedure is performed, as should factors such as the potential benefits and risks associated with screening, so that full informed consent is obtained.

In terms of guaranteeing quality of the screening test procedure, the general principles that facilities should follow relate to ensuring

- Capacity for screening;
- Quality of samples and examinations;
- Accuracy of analyses;
- Consistency in protocols;
- Competencies of health professionals.

### **Clinical component: follow-up, diagnosis and treatment**

If screening leads to an abnormal test result, protocols should be in place to ensure rapid follow-up and confirmation of diagnosis, carried out in accordance with evidence-based clinical guidelines. The key principles to consider when developing a programme include the following:

- An organised tracking and referral system which allows patients to receive specialist diagnosis as early as possible;
- Communication training for health professionals to prepare them to follow up and/or break negative news appropriately;

- Linkages with multidisciplinary teams that can make individualised decisions on patient management;
- Patient involvement throughout the process to reduce distress and ensure that individual wishes are respected.

### Quality control

Specific quality assurance mechanisms vary enormously by screening procedure, and programme planners are energetically encouraged to carefully heed comprehensive European guidelines. However, it is worth mentioning a few general essential foundations upon which any quality control programme should be based:

- Institutionalisation of quality, with careful attention from policymakers and programme managers as well as clear lines of responsibility and strict accountability mechanisms;
- Systematic implementation of all of the following: clinical guidelines, screening protocols, accreditation of professionals and facilities, monitoring and auditing schemes, and close linkage with a central cancer registry;
- Internal Quality Control procedures and rigorous External Quality Assessment Schemes in screening centres and laboratories, checking to ensure that wait times are limited, that screening equipment is up-to-date, that storage facilities for samples are adequate, that staff is well trained and that linkage with other health services—including primary and specialised care—is fluid;
- Close monitoring by public health specialists and health system managers, to ensure equitable and accessible population coverage as well as health system capacity to quickly and efficiently handle patient follow-up and treatment in case of an abnormal test result.

## 4. Indicators

Quality control also depends on the ability to measure results. These have at least three dimensions, all of which can help health system managers to identify the strengths and weaknesses of a screening programme: *structures*, *processes* and *outcomes*.

Data gathering systems for these indicators include registries of target population and screening activity, service user satisfaction surveys, quality audits for samples and diagnoses, mechanisms to monitor wait times, cancer registries with representative population coverage, and (to measure QALYs and cost-effectiveness) ad hoc methods and simulations models. It is very important to

ensure linkages between screening services/registries with population-based cancer registries.

The indicators in the below list have been compiled using the EUROCHIP indicators and the indicators from the guidelines; however, the list is not exhaustive, and planners are referred once again to the comprehensive quality assurance guidelines for more test-specific indicators (12–14).

Types of Indicators	Core	Additional/supplementary
Structural	<ul style="list-style-type: none"> <li>• The number of screening centres per capita</li> <li>• Number of available, qualified medical staff to carry out screening services and that staff's distribution throughout the territory</li> <li>• Administrative infrastructure to handle recruitment and follow-up</li> <li>• Number of training centres to ensure adequate human resources</li> <li>• Specific budget dedicated to cancer screening</li> </ul>	<ul style="list-style-type: none"> <li>• The location screening centres in relation to population (appropriate urban/rural balance)</li> <li>• The state or repair of screening equipment and laboratories</li> </ul>
Process	<ul style="list-style-type: none"> <li>• % of women that have undergone mammography*, disaggregated by population groups</li> <li>• % of women that have undergone cervical cytology examination*, disaggregated by population groups</li> <li>• % of persons that have undergone a CRC screening test*, disaggregated by population groups</li> <li>• Organised screening coverage (coverage by invitation)*</li> <li>• Screening recall rate*</li> <li>• Screening specificity* (the ability to designate an individual who does not have a disease as negative)</li> <li>• Screening detection rate*</li> <li>• Screening localized cancers*</li> <li>• Screening benign/malignant biopsy ratio*</li> <li>• Screening interval cancers*</li> <li>• Technical repeat rate</li> <li>• Additional imaging rate at the time of screening</li> <li>• Proportion of eligible patients reinvited within the specified screening interval (<math>\pm</math> 2 months)</li> <li>• Proportion of eligible patients reinvited within the specified screening interval plus 6 months</li> <li>• % expenditure for quality assurance</li> </ul>	<ul style="list-style-type: none"> <li>• Service user satisfaction</li> <li>• Wait times for screening and follow-up</li> <li>• Screening predictive value (the probability of having the disease, given the results of a test, directly determined by the sensitivity and specificity of the test and the prevalence of disease in the population being tested)</li> <li>• Screening sensitivity (the test's ability to designate an individual with disease as positive)</li> <li>• Further assessment rate</li> <li>• Rate of invasive investigations for diagnostic purposes</li> <li>• Proportion of malignant lesions with a pre-treatment diagnosis of malignancy</li> <li>• Proportion of image-guided cytological procedures with an insufficient result from lesions subsequently found to be cancer</li> <li>• Proportion of image-guided core biopsy procedures with an insufficient result or benign result from lesions subsequently found to be cancer</li> <li>• Surgical procedures performed</li> <li>• Interval between screening test and issue of test result</li> <li>• Interval between screening test and initial day of assessment</li> <li>• Interval between screening test and final assessment/surgery</li> </ul>

Outcome	<ul style="list-style-type: none"> <li>• Disease incidence†</li> <li>• Disease mortality (in screened and unscreened population)</li> <li>• Stage at diagnosis of screen-detected cancers</li> <li>• Population coverage (%)</li> <li>• Cost-effectiveness</li> </ul>	<ul style="list-style-type: none"> <li>• Quality-adjusted life years (QALYs) gained.‡</li> <li>• Interval cancer rate</li> <li>• Detection rate</li> <li>• Proportion of screen-detected invasive cancers <math>\leq 10</math> mm</li> <li>• Proportion of screen-detected cancers that are invasive</li> <li>• Proportion of screen-detected cancers with lymph node metastases</li> </ul>
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\*EUROCHIP indicator

† Incidence should actually rise when a programme is first implemented, as this will indicate that more cancers are being detected. Once the programme has been fully rolled out, incidence should stabilize somewhat for breast cancer (also depending on the effectiveness of primary prevention measures), or decrease in the case of cervical or colorectal cancers, whose long latent period should allow detection of pre-cancerous lesions before a tumour actually forms.

‡ Although the calculation of QALYs is impaired by certain methodological challenges, it remains important to estimate QALYs for all patients who receive a positive diagnosis in order to ensure that life years are not presumptively gained at the expense of quality-of-life. This can happen if over-diagnosis or over-treatment lead to painful and distressful interventions among many patients who see no commensurate improvements in their life.





Part II.

# **Integrated Care**



# Diagnosis and Treatment

*Josep Borras, Joan Prades*

## 1. Background

Cancer care is increasingly complex due to the number of disciplines that should be involved in the diagnostic and therapeutic process as well as the progress made in research, which has resulted in continuous innovations with different levels of evidence and impact on outcomes. All these factors have made the organisation of the delivery of cancer care a challenge for health-care services, especially in terms of coordinating health professionals and levels of care involved in the patient pathway over the course of the diagnostic and therapeutic process (23). Crosscutting themes include a multidisciplinary approach to the management of the cancer patient; integration of health services; the establishment of Centres of Expertise (CoE) and of national and European reference networks (ERN) for the provision of complex procedures (24) and the treatment of rare cancers; and the assessment of the quality of care (25). In parallel, progress in survival thanks to early diagnosis and improvements in therapy have produced a renovated interest in survivorship issues and quality of life of cancer patients (see the following chapter).

Resources to cope with these challenges are always limited, so policymakers are charged with identifying areas for improvements, establishing priorities and selecting actions that could offer a clear population benefit and improve the experience of care for patients. These actions should be implemented in an organised way and properly evaluated.

Lastly, a guiding principle should be the integral involvement of patients in the process of care. Efforts must be made to ensure a model of care based on fluid

communication with patients and shared decision-making whenever possible and appropriate. To that effect, patients' treatment and care preferences (particularly those affecting quality of life) should be discussed with them before making clinical decisions. Likewise, patients should have access to a second opinion and the opportunity to choose from different treatments and providers.

## 2. Planning for diagnosis and treatment of cancer patients

### Assessment of the situation

In order to assess the priorities for cancer care planning (26), it is necessary to carry out an analysis of the information on the quality and outcomes (short and long term) available in the country as well as the existing resources for cancer diagnosis and treatment. Relevant aspects include:

- Incidence and survival data from a population-based cancer registry. The EURO CARE high resolution studies and similar studies undertaken in a single country have shown that cancer registries can collect stage and treatment information. It is important to collect information on stage at diagnosis and treatment and to ensure the necessary support to the cancer registry in order to collect comprehensive, good quality data on these clinical variables.
- Other clinically relevant information includes discharge information, such as number of complex surgical procedures (e.g. surgery with a curative aim for lung, brain, pancreatic, oesophageal, stomach and rectal cancer as well as liver metastasis) per hospital; surgical mortality up to 30 days post-op; radiotherapy activity; chemotherapy treatments; etc.
- Resources for diagnosis and care include (see also Resources chapter):
  - Description of the resources for treatment including:
    - Number of hospitals offering cancer care, classified according to the diagnostic facilities (Pathology and Imaging);
    - Radiation Oncology resources (equipment, professionals and activity);
    - Medical oncology resources (day hospital, professionals, activity);
    - Surgery (type of procedures performed, volume and short term outcomes);
    - Genetic counselling units;
    - Resources for molecular genetic analysis.
  - Organisation of care:
    - Multidisciplinary tumour boards;

- Relation between levels of care;
- Networks of hospitals, if available;
- Specific information on diagnosis and treatment of paediatric and rare tumours;
- Existence of clinical guidelines;
- Evaluation of implementation of the clinical guidelines, if available;
- Identification of relevant stakeholders: clinicians and cancer related professionals, scientific societies, patient groups, cooperative groups, health care providers, governmental department.

### **Prioritisation and goal-setting**

There is generally a shortage of resources in providing all that it is possible to deliver in cancer care, and it is not feasible to cope with all detected needs at the same time; some criteria for prioritisation should be in place in order to propose actions in a cancer plan (26). Although these criteria may depend on context, several aspects should be considered:

- Public health importance of the cancer site under consideration and the potential public health impact of the proposed intervention;
- Budgetary impact of the action proposed and a cost-effectiveness analysis, if possible;
- Feasibility of implementation from the perspective of health professionals available with the appropriate expertise and resources required; equity of access assured; implementation strategy planned;
- Dissemination of the strategy among stakeholders involved and society;
- Agreement of relevant stakeholders, including scientific societies and patient representatives;
- Assessment of the action included in the planning process.

In general, the question to answer is: Are the proposed actions and objectives aligned with the global cancer control plan with a reasonable budget and evaluation planned?

## **3. Programme elements**

### **Improving diagnosis of cancer**

*Waiting times and rapid fast-track systems up to first-treatment delivery*

One of the most valued cancer services is rapid access to a high quality diagnosis of cancer, provided that treatment can also be offered in case of a

positive diagnosis (27). Elements contributing to fast-track systems include the following:

- Explicit and reasonable waiting times for diagnostics and therapies for cancer patients;
- Well-founded criteria for clinical suspicion of cancer for the main tumours, in conjunction with the reference diagnostic test and the priority/preferential circuit for conducting the diagnostic test in question;
- Agreement between primary health care physicians and hospital specialists about symptoms included, role in the diagnosis pathway and point of access to diagnostic confirmation process;
- Strengthened coordination between specialised and primary health care;
- Feasibility of sharing medical data between health care professionals of both levels of care (beyond information system capacity);
- Prompt treatment upon diagnosis;
- Applying a learning-cycle approach in order to maintain the effectiveness of the implemented mechanisms.

### *Diagnostics*

- Monitored waiting times for diagnostic procedures;
- Synoptic (Standardized) Pathology Reporting. Clinicians depend on pathology reports to confirm cancer diagnosis and decide on the most appropriate course of treatment, making high-quality pathology reporting essential;
- Double reading for rare tumour diagnostic process, done by an expert pathologist working in a centre of expertise.

## **Improved access to high quality cancer treatment**

Cancer treatment has several features that makes planning and organisation of health services very relevant to delivering high quality cancer care beyond the individual quality of each therapy, namely, the need to combine different therapeutic strategies, and to spur the integration of innovation and uptake of research outcomes into care, in the context of a progressive personalisation of the therapy (28). In this section, the specific therapeutic strategies are reviewed, while below we detail the aspects more related to the coordination of care.

### *Clinical Practice Guidelines (CPG)*

Treatment-related decisions should be based on evidence-based, clinical practice guides and protocols pertaining to each hospital for each type of tumour that should be consistent with the health-care level guidelines. In fact, the

classical aim of CPGs is to propose the best care for a specific patient profile. However, from a cancer control perspective, the population benefits involved in the cancer care should be considered when choices among different options of treatment are proposed in the CPG.

Existing guidelines may need to be reviewed and/or updated with a predefined interval of time, using a multidisciplinary approach and taking into account any evidence based European guideline available. These should be adapted to local resources, having concern for the health-care organisation of the cancer care delivery.

As important as the need to have high quality CPG for major tumour sites, there is also a proactive need to assess their implementation and monitoring of their uptake. Clinical audit methodologies based on a predefined set of variables and indicators are very useful for this assessment.

### *Surgical treatment*

Highly specialised surgical procedures could be concentrated in specific hospitals in order to increase expertise and improve outcomes, provided an adequate quality assurance system is also in place (29–32). This concentration should be done in the context of easy access and ongoing communication to the referral services, favouring the devolution of patients when possible. The clinical decision-making process should be multidisciplinary and outcomes assessed.

Concentration of surgical services requires (1) high volumes of procedures; (2) necessary infrastructure and (3) human resources to ensure high quality. Thoracic, brain, hepato-pancreatic-biliary (HPB) and oesophageal surgical procedures with a curative intent are among some of the procedures that may be performed in designated reference hospitals.

Other tumours that require multidisciplinary involvement in the health-care processes, such as sarcoma and bone tumours, rectal cancer, neuro-oncology or neuroendocrine tumours, could also benefit from such an approach.

### *Medical oncology*

Points to consider include the following:

- The process of appraising new cancer drugs;
- Close monitoring of chemotherapy usage;
- Access to new treatments decided in agreement with the available resources, evidence of impact on outcomes and capacity to ensure equity of access. All essential cancer drugs should be available (see chapter 8 on resources);
- Cost-effectiveness and budgetary impact of new cancer drugs;

- Standards of practice for the organisation and delivery of systemic treatment (chemotherapy).

### *Radiation therapy*

- Long term planning of radiotherapy facilities according to needs assessment. Investment in radiotherapy facilities should be planned in a timely way in order to avoid unnecessary delays in replacing and updating technology;
- Access to high quality radiotherapy equipment. Updated technology available: Intensity Modulated Radiation Therapy (IMRT) and Image-guided radiotherapy (IGRT) for patients that may benefit from such techniques;
- Review quality control and availability of evidence-based standards of practice in radiotherapy centres.

### *Paediatric oncology*

Standards of care for children with cancer of the Society for Paediatric Oncology Europe (SIOPE) should be reviewed and implementation included in the planning of resources and organisation of the delivery of care for children with cancer in the country (33, 34). Other key issues involved include:

- Volume effect in paediatric oncology;
- Existing national and regional cancer registries;
- Staffing challenges and educational opportunities;
- Core elements for adequate paediatric cancer treatment;
- Social care aspects (including continuous education during treatment);
- The role of parents and patient organisations;
- Methods and tools for integrating standards into national guidelines.

### *Rare tumours*

Several countries are considering the problems posed by rare tumours in terms of complexity of the diagnostic and therapeutic process in a specific way in order to cope with the challenges posed by the singularity of most of these low frequency tumours. There is no internationally agreed definition of rare tumours, although in the RARECARE project they have been defined as those with an incidence  $\leq 6/100,000$ . However, it should be mentioned that the rare diseases definition agreed by the European Union is based on prevalence ( $<6/10,000$ ) (35).

Rare tumours may be argued to possess a 'dual identity' in the sense that they come under the scope of both the 'cancer' and 'rare disease' fields. It is



important to ensure that rare cancers are adequately incorporated into both of these (usually distinct) fields, to ensure that they are not overlooked.

Major points in this area are as follows (36):

- Representing approximately a fifth of all tumours, rare cancers are both a highly pertinent concern for European cancer patients and one that cannot easily be addressed without joining forces. The 20% figure of rare cancers includes solid adult cancers (16%), malignant haematological disease (4%) and malignant paediatric tumours (less than 1%);
- Each of these groups is characterised by specific features and patient needs, requiring the involvement of diverse medical specialities;
- Models developed for rare cancers are also interesting in the study of frequent cancers, especially when molecular characteristics define subgroups of patients who may be responsive to targeted therapies. Subsets of rare cancers may therefore be determined within the broader category of frequent tumours according to the expression of specific biomarkers.

The initiative of Rare Tumours in Europe promoted by ESMO and ECPC has proposed a list of criteria for dealing with this group of tumours that could be reviewed in order to set the priorities in this area (<http://www.rarecancerseurope.org>). Low incidence is a major obstacle to conducting clinical trials to develop effective treatments. One way to overcome this obstacle would be to establish centres of excellence for rare cancers and international collaborative groups to network centres across the EU to thereby achieve necessary organisational structure, critical mass and patients for carrying out clinical trials, developing alternative study designs and methodological approaches to clinical experimentation and improving accuracy and standardisation of staging procedures for rare cancers.

Past and present EU-level initiatives in the rare disease field could be relevant here, as considerable work has been undertaken (and is ongoing) to define optimal models for healthcare organisation and collaboration between national systems, in order to support the needs of rare disease patients and reduce inequalities across the EU. The European Union Committee of Experts on Rare Diseases (EUCERD) adopted *Recommendations on Quality Criteria for Centres of Expertise for Rare Diseases in Member States*, which could be of relevance for the creation of centres of excellence for rare cancers. The actual process of designating national centres of expertise is ongoing.

Similarly, the rare disease field is exploring how to utilise the experiences of disease-specific networks (established through limited-term funding from the EU) to create sustainable networks between these centres or 'nodes' of concentrated expertise. As per Council Recommendation 2009/C 151/02, all EU Member States were expected to elaborate National Plans or Strategies for rare diseases by the end of 2013, designed to guide and structure relevant rare disease activity within the framework of the national health and social system.

This process is ongoing; however, in generating, implementing and evaluating these Plans and Strategies, Member States will ideally consider any potential cross-over concerning rare cancers.

The EU directive on cross-border health-care also provides a further impulse for pan-European action in this area, setting the framework to build European reference networks for rare diseases (24). It aims at efficiently facilitating access to the required expertise in reference centres across Europe.

## **Increased coordination and clinical assessment**

### *Multidisciplinary teams (MDTs)*

Optimal decision-making in the diagnosis, treatment and support of cancer patients is being increasingly associated with multidisciplinary teams (MDTs) (37). Cancer care involves a growing number of specialists and health professionals as intervention areas expand to encompass psychosocial support, genetics and frailty aspects (among other areas) and consensus decisions are needed at all stages of care. As the care pathway becomes more complex, the potential for miscommunication, poor coordination between providers and fragmentation of services increases (38). This constitutes a challenge for patients and families as well as for caregivers.

Basic principles for establishing an MDT include the following:

- Set up tumour boards at each centre, where none to exist, to evaluate all of the cases diagnosed and/or treated by all the specialists involved in the respective cancer diagnosis and treatment process;
- Patients' early access to the MDT should ensure that appropriate treatment is selected based on the preoperative assessment of imaging and pathology results. After staging, MDT consensus and patient consent on an evidence-based treatment plan is required for every cancer patient;
- Because of the consensus mechanisms that MDTs imply, including verification that decisions are consistent with available evidence, fostering MDTs is imperative to ensuring appropriate clinical decisions;
- The roles of each professional must be defined, especially that of the tumour board coordinator. This individual should be in charge of securing professionals' attendance, preparing patient lists and effectively implementing the decisions made by the team. In agreement with the team, the coordinator should also arrange the involvement of other specialists as needed;
- The role of nurse case managers has been extensively implemented in order to coordinate patients' care management during the diagnosis and active treatment phases. Although different approaches to improve coordination of the process of care could be envisaged, the role of nurse case

managers, a reference for both patients and professionals, is the most frequently implemented and should be considered;

#### *Networking collaboration for clinical management*

The need for coordination of cancer care among different levels of complexity has spurred the assessment of diverse organisational approaches as a way to implement formal cooperation channels between the providers of a given catchment area. Professional-based networks, reinforced by meso-management agreements and regional policies, have been the most frequent organisational approach (e.g. Rhone-Alps, Catalonia, Piedmont, Flanders, Tuscany, etc.) (36).

The positioning of existing organisations may need to be explicitly clarified in terms of their role in providing cancer services:

- High-cost, high-complexity services; highly centralized/few centres, e.g., stem cell transplant;
- High-complexity services; centralized regionally, e.g., head and neck cancers, gynaecological oncology or rare tumours;
- High-volume services provided in disseminated model, e.g., most breast, colorectal, prostate cancer care;
- The potential for inter-organisational collaboration (through networks or partnerships) may also be assessed to enable complex procedures to be carried out by specialists working at different sites of the network;
- A networking model could be identified for regional cooperation (cancer network, cancer centres and local satellites, etc.), respectful of professional expertise distribution and ensuring equity of access to high quality of care;
- It is important to focus the international collaboration among EU countries especially with regard to childhood and rare cancers within the framework of the above mentioned cross-border healthcare directive.

#### *Surveillance after cancer treatment*

The follow-up, after having fully completed the multidisciplinary treatment, should be coordinated among all the professionals involved in order to avoid unnecessary duplications in visits or tests, preferably by a single professional chosen by the specialists involved within the framework of the multidisciplinary team.

Interfacing information alerts are one useful tool by which to engage primary care physicians with the treatment outcomes of the acute process of care.

**Strengthen the patient's role**

The importance of patients' role in their care process is progressively gaining recognition in clinical practice. Furthermore, the patient's role should be envisioned in all the steps of the plan, from its development to the evaluation.

From the initial need to provide clear and trustworthy information about the benefits and risks of the treatment and the prognosis of the cancer, to the involvement in shared decision-making, the role of patients is changing, and this should be recognized in the cancer plan accordingly.

Elements may include:

- Information provided to patients using formal and interactive techniques based on good practice guidelines designed by specialists;
- Up-to-date and comprehensive reference information on medical, social, legal and practical issues concerning different forms of cancer;
- An overall report provided to the patient upon completion of the treatment process.

**4. Indicators**

Different types of indicators could be helpful for policy makers in order to assess the progress of cancer care (39–41). The key issue is to establish the mechanisms for collecting data and the methodology for evaluating the clinical results for the indicators selected. Special efforts should be made to support the collection of clinically relevant data by population-based cancer registries, such as stage at diagnosis and type of treatment (42).

Physicians involved in cancer care and control must have access to their own performance data.

Type of indicator	Core	Additional/Supplementary
Structural	<ul style="list-style-type: none"> <li>• Number of hospitals offering cancer care, classified according to the diagnostic (Pathology and Imaging) and therapeutic facilities</li> <li>• Radiation Oncology resources (equipment, professionals and activity, per population)</li> <li>• Medical oncology resources (day hospital, professionals and activity, per population)</li> <li>• Surgery (type of procedures performed, activity, professionals, per population)</li> </ul>	<ul style="list-style-type: none"> <li>• Genetic counselling units</li> <li>• Resources for molecular genetic analysis</li> <li>• Existence of evidence-based, multidisciplinary clinical practice guidelines (CPG) by tumour site, regularly updated (e.g., 2 years)</li> <li>• Population-accountable cancer services organisation: (1) peers or 'hub and spoke' models of networks; (2) existence of Comprehensive Cancer Centres (CCCs); (3) inter-professional networks for diffusion of knowledge and/or second -opinions and/or patients' referral in order to ensure equity of access to high quality of care</li> </ul>
Process	<ul style="list-style-type: none"> <li>• Clinical indicators are relevant such as percentages of breast cancer treatments performed with conservative surgery</li> <li>• Interval of time between symptom suspicion/referral by a physician detection and confirmation of the diagnosis (patient and healthcare/system provider factors)</li> <li>• Delays in treatment delivery in surgical procedure, chemotherapy and radiotherapy treatments (disease and healthcare/system factors)</li> <li>• Conformity of pattern of care between CPG and clinical practice (usually involving chart review)</li> <li>• Specific population accountable information/databases on diagnosis and treatment of paediatric patients</li> </ul>	<ul style="list-style-type: none"> <li>• Multidisciplinary tumour boards: % of patients' coverage by tumour site</li> <li>• Specific population accountable information/databases on diagnosis and treatment of rare tumours</li> <li>• Perception on the quality of information and communication received along the cancer care process, assessing specifically continuity of care</li> </ul>

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| <ul style="list-style-type: none"><li>● Outcome</li></ul> | <ul style="list-style-type: none"><li>● Survival rates by tumour site and according to the stage in the diagnosis if available (1 and 5 years survival)</li><li>● 30-day post-operative mortality rate (or within the same hospital admission) of the complex surgical procedures performed for curative purposes in oesophageal, stomach, pancreatic, rectal, lung cancers, neuro-oncology and liver metastasis</li><li>● Recurrence of cancer and quality indicators associated with these procedures should be recorded using international comparable data (EURECCA variables and indicators could be used as reference)</li></ul> | <ul style="list-style-type: none"><li>● Perceived satisfaction from patients along the cancer care pathway</li></ul> |
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# Psychosocial Oncology Care

*Luzia Travado, Miriam Dalmás*

## 1. Background

Cancer and its treatment have a significant impact on the quality of life of patients and their families and carers. A substantial number of cancer patients and survivors experience high levels of cancer-related distress (30–45%) (43, 44), and may develop more serious mental health problems such as adjustment disorders, anxiety disorders and depression (45–47). These conditions negatively impact on clinical outcomes such as treatment compliance, survival and quality of life and require specialised psychosocial care (48). Psychosocial problems also affect the patient's family with a consequent increase in emotional distress among the patient's caregivers that may continue into the bereavement period, with greater risk of complicated or traumatic grief among relatives (49). Patients' and their family supportive care needs must be central component of quality comprehensive cancer care (50).

Psycho-oncology addresses a range of psychosocial, behavioural, spiritual and existential dimensions that the patient and family face throughout the cancer care continuum. Therefore a primary goal is that all cancer patients and their families receive optimal psychosocial care at all stages of the disease and into survivorship (51).

Despite the major implications of psychosocial morbidity for clinical care, psychosocial issues in cancer are still all too often dismissed or underestimated, and not yet regularly offered to cancer patients (52, 53).

The significance of the psychosocial aspects of cancer and its treatment is growing in importance owing to the growing numbers of cancer survivors in European countries.

The Institute of Medicine Report on *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs* (2008) (50) recommended:

- Promotion of effective communication between patients, caregivers and health care professionals;
- Routine identification of distress and supportive care needs;
- Access to psychosocial care for patients and caregivers;
- Support for patients and caregivers to cope with the multifaceted disease consequences;
- Coordination of psychosocial and biomedical care;
- Continuous evaluation of psychosocial care programmes.

In 2009, the International Psycho-Oncology Society (IPOS) ([www.ipos-society.org](http://www.ipos-society.org)) proposed a new standard in quality cancer care (54) endorsed by the UICC and 74 other international organisations and scientific societies related to cancer treatment and care, which states:

- Quality cancer care today must integrate the psychosocial domain into routine cancer care;
- Distress should be measured as the 6th vital sign after temperature, blood pressure, pulse, respiratory rate and pain (55, 56).

## 2. Programme elements

It is recommended that the NCCP includes the following elements for quality psycho-oncological care:

- Training of health care professionals in the psychosocial aspects of cancer;
- Inclusion of routine Screening for Distress, the 6th Vital Sign\* of cancer patients;
- Employ evidence-based treatments for symptoms and psychosocial needs; identified through distress screening;
- Development of minimum practice standards in psycho-oncology services;

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\* Distress is an unpleasant emotional experience of a psychological, social and/or spiritual nature which extends on a continuum from normal feelings of vulnerability, sadness and fears to disabling problems such as depression, anxiety, panic, social isolation and spiritual crisis (NCCN, 1999). Research has shown that distress is highly prevalent in cancer patients and if untreated can negatively impact patients' clinical outcomes. The application of assessing physical distress, now labelled Vital Signs, has become standard practice. Vital signs are routinely taken by health professionals in order to assess the most basic bodily functions, an essential part of a patient's case presentation. Because of its prevalence and under-treatment, pain was designated the 5th Vital Sign. Due to the fact that distress is also under-assessed and under-treated, it has been designated the 6th Vital Sign. It has also been incorporated by accreditation in Canada as well as other countries. It represents a standard in psychosocial Oncology and has been widely endorsed by over 75 cancer societies and organisations internationally.



- Implementation and integration of psycho-oncology programmes into cancer multidisciplinary teams;
- Engagement of resource procurement sector and service providers to ensure that comprehensive cancer care includes psychosocial care as standard.

An important overall consideration is the differentiation and provision of specialised services for and support to paediatric cancer patients and their families. Children will likely have very different presentations of psychosocial symptoms and morbidity from adult cancer patients.

### **Training of healthcare professionals working in close contact with cancer patients in psychosocial aspects and communication skills**

Training in communication skills contributes to better patients' clinical outcomes (57, 58) and can reduce cancer physicians' burnout (59). Promoting effective communication between patients, caregivers and healthcare professionals can be achieved through:

- Including communication skills training in undergraduate and postgraduate curricula for physicians, nurses, and other allied health care professionals in cancer care;
- Continued professional development programmes in psychosocial oncology in all cancer settings.

### **Screening for Distress, 6<sup>th</sup> Vital Sign and assessment of psychosocial needs**

Methods for assessing distress and psychological morbidity in cancer patients are often not routinely employed in cancer settings. Addressing the often-neglected aspects of patients' and families psychosocial needs should be routine in clinical practice. There is evidence this has positive benefits for patients' clinical outcomes (60) and can be used as an endpoint of cancer care, as a useful indicator of the quality of performance in the services.

Application of methods for screening for distress that have been developed, tested, and validated in many European countries and worldwide (61).

Integration of psychosocial care professionals in cancer care (multidisciplinary teams) for proper identification, referral and treatment of patients to more specialised services according to their needs such as psycho-oncology care.

### **Evidence-based psychosocial interventions**

Psycho-oncology interventions have proved to be effective in preventing and reducing severe distress and psychological morbidity and in improving patients' clinical outcomes including quality of life and survival (62–64). A wide range of psycho-oncology approaches and treatments such as educational and psychological support interventions, counselling, coping skills and psychotherapy (individual, group or family) can be employed.

The NCCP should consider and include the following:

- Professionals with expertise in psycho-oncology in the multi-disciplinary treatment team (MDT), to screen for distress and psychosocial needs of the patients and their families, and provide psychosocial interventions accordingly;
- Provision of specialist training for the identified professionals to enable recruitment, continued development and retention of these experts (promote certification through post-graduation qualifications in psycho-oncology);
- Assessment of the demand for psycho-oncology care to determine the capacity of the service required (number of professionals and level of their expertise according to the number of cancer patients - new cases and prevalent cases);
- Use of psychosocial oncology clinical guidelines for cancer care;
- Provision of a protected budget for psychosocial care services on a regular annual basis;
- Follow-up and quality assurance, with an ongoing evaluation of the service (in line with the evaluation of all the other cancer care services).

### **Development and implementation of psycho-oncology services and integration in multidisciplinary teams**

It is recommended that psycho-oncology services be located in national cancer care facilities. The allocation of specialised healthcare professionals in psycho-oncology for these services and a budget for its sustainability will be the best way to ensure service provision and quality of services.

MDTs have been identified as the best approach to organising and coordinating cancer care in a way that consistently brings together all healthcare professionals involved in cancer diagnosis and treatment, which also includes psychosocial care specialists (24, 37).

As stated in the EPSCO 2008 document “to attain optimal results a patient-centered comprehensive interdisciplinary approach and optimal psychosocial care should be implemented in routine cancer care, rehabilitation, post-treatment and follow-up for all cancer patients (65).

### 3. Indicators

Types of Indicators	Core	Additional/ Supplementary
Structural	<ul style="list-style-type: none"> <li>• Inclusion of the psychosocial care services for cancer patients in the National Cancer Control Plan</li> <li>• Existence of the psychosocial care services/units in the national healthcare system</li> <li>• Number of psychosocial care professionals working in cancer care services</li> <li>• Continuity in participation of psychosocial care specialists in the multi-disciplinary team meetings per service and per hospital treating cancer patients</li> <li>• Inclusion of <b>communication skills training (CST)</b> in curricula and continued professional development programmes for medical doctors and nurses: <ul style="list-style-type: none"> <li>• Undergraduate curricula</li> <li>• Post-graduate curricula</li> <li>• Continued Professional development programmes</li> </ul> </li> <li>• Inclusion of <b>psychosocial care</b> in curricula and continued professional development programmes for medical doctors and nurses: <ul style="list-style-type: none"> <li>• Undergraduate curricula</li> <li>• Post-graduate curricula</li> <li>• Continued Professional development programmes</li> </ul> </li> <li>• Having a budget for psychosocial care services</li> </ul>	<ul style="list-style-type: none"> <li>• Number of cancer care facilities with psychosocial care services per number of cancer care facilities in the country</li> <li>• Availability of post-graduation courses and/or MSc courses in psycho-oncology provided by Universities</li> </ul>
Process	<ul style="list-style-type: none"> <li>• Proportion of cancer patients that are screened - routinely and on a regular basis - for distress against the number of cases of cancer per year</li> <li>• Proportion of cancer patients that receive psychosocial care</li> </ul>	<ul style="list-style-type: none"> <li>• Cost-offset analyses to clarify benefits</li> </ul>
Outcome	<ul style="list-style-type: none"> <li>• Patient satisfaction</li> <li>• Quality of life</li> </ul>	<ul style="list-style-type: none"> <li>• General well-being</li> </ul>



# Survivorship & Rehabilitation

*Marc Van den Bulcke, Regine Kiasuwa*

## 1. Background

Although cancer mortality rates are declining in developed countries, incidence and prevalence rates are still increasing, leading to a growing population of people living with or beyond cancer. While the definition of a “cancer survivor” is often used broadly in a non-clinical context to describe anyone who has received a cancer diagnosis, for our purposes, the term “cancer survivorship” may be defined as the clinical period between primary curative treatment and recurrence and/or death (66). The present chapter will focus on this part of the disease trajectory and the needs of the individuals who are going through it.

Cancer and its treatment can cause enduring impacts on the patient’s overall quality of life (QoL). All of these impacts and their associated needs should be addressed within the scope of a national cancer control plan (NCCP) to optimally support cancer patients in fully regaining the capacity to undertake their daily social and professional activities and increase their overall QoL (23).

## 2. Planning: needs assessment, prioritisation and goal-setting

Cancer treatments may have side effects that can impede or constrain the daily life of cancer survivors. These effects can vary according to the type of treatment, the age and the social environment of the patient (67–71). The most common late and long-term effects include:

- Fatigue;
- Pain;
- Sleep insufficiency;
- Depression;
- Reproductive issues;
- Negative self-esteem;
- Cognitive impairments; and
- Emotional and social difficulties.

The implementation of survivorship strategies first requires an assessment of the unmet needs of those patients. Prevalence and survivorship data from cancer registries can help characterise the target population, including survivors' age, type of cancer, and type of treatment. These data should be paired with results from a needs assessment analysis (for example, through a survey) on new cancer survivors as well as those who finished curative treatment several years previously, to understand what survivors perceive as their greatest needs. The assessment has to be as comprehensive as possible, including the specific aspects related to the three basic age groups: children (72), adults and the elderly (see table 1). Cancer-specific issues should also be taken into account; for example, specialised training for social care professionals may be called for in the case of survivors of rare cancers. Indeed, the European Union Committee on Rare Diseases (EUCERD) Joint Action ([www.eucerd.eu](http://www.eucerd.eu)) is undertaking work in articulating specific areas of action.

## Prioritisation

Based on the data collected in the needs assessment analysis, planners should keep the following in mind when deciding what rehabilitation and survivorship services to establish or expand, and in what order and magnitude:

- *Feasibility.* The feasibility of measures to enhance the survivorship needs to be measured. The feasibility assessment will include the availability of human resources (e.g. psycho-oncologists, occupational therapists, social workers, etc.) and the improvement of already existing structures and policies;
- *Risk of relapse.* Clinical rehabilitation services aimed at decreasing risk of relapse are of utmost priority. This category includes not only early detection and monitoring of tumours, but also health promotion counselling, to assist with smoking cessation, weight loss or other risk factors; and
- *Return to daily life.* Any physical or psychological effects that impede the survivor's reincorporation into school or work will have collateral effects throughout society, in lost opportunities, decreased productivity and greater long-term demand for other health and social services. Thus,

**Table 1.** Common survivorship issues, by age group

Children and survivors of childhood cancers	Adults	Elderly
<ul style="list-style-type: none"><li>• Problems with growth, development and neuro-cognitive functioning</li><li>• Psychological side-effects</li><li>• Long-term side-effects of cancer treatments</li><li>• Impaired education opportunities</li><li>• Physical disabilities</li><li>• Family/peer relationships</li><li>• Vocational and employment opportunities</li><li>• Access to services such as insurance, financial and health care</li><li>• Increased risk for cancer</li><li>• Follow-up needs</li></ul>	<ul style="list-style-type: none"><li>• Health and well-being (sleep, diet, exercise, smoking, quality of social relationships and support)</li><li>• Medium and long-term symptoms (fatigue, cognitive limitations, distress, pain, sleep disturbance, dyspnoea)</li><li>• Social and functional demands (discrepancies between individual's functional capabilities and the socio-professional demands)</li><li>• Work ability (retention of employment, re-employment)</li><li>• Economic factors (loss of wages, costs of caring services)</li><li>• Follow-up needs</li></ul>	<ul style="list-style-type: none"><li>• Management of old and new chronic conditions</li><li>• Diminished physical ability</li><li>• Comorbidities</li><li>• Social and emotional difficulties</li><li>• Follow-up needs</li></ul>

rehabilitation and survivorship services should prioritise areas of work that allow cancer survivors to healthily resume the activities they carried out prior to diagnosis.

**3. Programme elements**

To facilitate the return of cancer survivors to social life—including work—a comprehensive cancer rehabilitation initiative should follow four steps:

- Problems evaluation: the multidisciplinary team evaluates the sum total of problems that a survivor is facing;
- Address/treat chronic effects: the plan should consider the adverse effects of cancer and cancer treatment, as well as any co-morbidities affecting the rehabilitation process, especially chronic disease conditions;
- Encourage/support self-management: Programmes and carers need to encourage and support self-management, including through skills development and social support. This step is crucial to decrease the risk of additional late effects;

- Return to work/to social life: the final aim is optimising the functional status of patients and their quality of life by preserving or regaining their abilities to return to work or pursue their daily activities.

These steps hinge on the capacity of health and social systems to provide the following, which are covered in more detail below:

- Patient-centred cancer rehabilitation programmes;
- Holistic social support to patients and families;
- Self-management programmes.

### **Patient-centred cancer rehabilitation programme**

All rehabilitation plans should be patient-centred and constitute a multidimensional support between patient, care professionals and the patient's social network (especially close relatives). Measurement of distress between diagnosis and first treatment is very important (60, 61). A multidisciplinary approach, assessing and treating the chronic effects of cancer and preventing or mitigating the effects of late-occurring sequel is generally considered to be the most effective approach for cancer rehabilitation (71). Such an approach should also aid the patient in regaining as much autonomy as possible (73).

Ideally, a personalised rehabilitation plan, including physical therapy and psychosocial support, should already exist when the patient begins treatment; transversal organisation of cancer rehabilitation with other disease rehabilitation programmes may facilitate a more comprehensive care approach, reducing the impact for the patient and streamlining use of resources.

### **Holistic social support to patients and families**

In addition to clinical rehabilitation services, including psycho-oncological support, it is necessary to ensure coordination between other health and social services for cancer survivors. This will often depend on the capacity of community care workers—particularly the family physician—to help survivors identify the services they need. Some of these may include:

- Couples or family counselling;
- Psychological and spiritual counselling;
- Occupational or physical therapy;
- Genetics counselling;
- Pain clinics;
- Nutrition or dietary therapy;
- Smoking cessation.



## Self-management programmes

The growing prevalence of cancer patients within the population implies the need for a change in the management of rehabilitation and survivorship in general. Services based in hospitals should be reduced in favour of increased self-management, supported by general physicians and specialists when needed, cancer patient groups, social workers and relatives. When developing a self-management regime, particular attention should be paid to the educational level, the age and the socioeconomic status of the patient.

A self-management programme (74) could include the following:

- Workshops (75) and/or written informational materials to educate patients on what to expect after curative cancer treatment is over;
- Provision of written materials to assist survivors in self-management (e.g., dietary journals, questionnaires to help survivors articulate common physical or psychosocial concerns);
- Establishment of survivor support groups, including for relatives and informal carers;
- IT tools to assist survivors with lifestyle modification, diet, therapeutic adherence, care plans and psychological support.

## 4. Indicators

Information about indicators (73) are in general collected through interviews organised across the country with common questionnaires or by specific surveys directly addressed to cancer survivors identified through cancer registry databases (76). Moreover, the development of quality assurance guidelines could be a very useful aid in increasing the quality of rehabilitation programmes.

Types of Indicators	Core	Additional/supplementary
Structural	<ul style="list-style-type: none"> <li>• Coverage for mental health and psychosocial care</li> <li>• Coverage for reconstruction and rehabilitation</li> <li>• Imaging technology</li> <li>• Integration of survivorship in health-care system</li> <li>• Training for health care professionals</li> <li>• Cancer prevalence*</li> </ul>	<ul style="list-style-type: none"> <li>• Genetic testing</li> <li>• Specialised models of care i.e. Patient-Centred Medical Home</li> <li>• Specialised survivorship clinics</li> </ul>

Process	<ul style="list-style-type: none"><li>● Treatment to prevent cancer recurrence</li><li>● Surveillance for recurrence</li><li>● Screening for second malignancies</li><li>● Assessment of symptoms and late effects of therapy</li><li>● Assessment and management of psychosocial distress</li><li>● Perceived QoL of cancer patients before and after rehabilitation support (measured at regular intervals)</li><li>● Qualified prevalence (number of patients at an exact date who have had recurrence, metastasis, other tumours or totally recovered)*</li></ul>	<ul style="list-style-type: none"><li>● Availability of rehabilitation service for specific cancer sites*, including:</li><li>● Speech &amp; language therapy for head and neck cancer patients</li><li>● Physiotherapy for cancer patients</li><li>● Dietician therapy for gastrointestinal cancer patients</li><li>● Psychological support for all cancer patients</li></ul>
Outcome	<ul style="list-style-type: none"><li>● Disease-free survival</li><li>● Overall survival</li><li>● Functional status</li><li>● Rate of return to work among working-age survivors*</li><li>● Quality of Life*</li><li>● Satisfaction</li><li>● Cost</li></ul>	<ul style="list-style-type: none"><li>● The number of policies related to cancer survivorship at state and/or regional levels</li></ul>

\*EUROCHIP indicator

*Adapted from: (73)*

# Palliative and end-of-life care

*Miriam Dalmás*

## 1. Background

Palliative care is an essential component of cancer care. Palliative care is often associated with cases of advanced cancer. However, WHO recommends that palliative care should begin early in the course of the illness, thus forming part of the overall intervention protocol (77). Despite extensive efforts to prevent and cure cancer, the average five-year survival from cancer only reaches between 50% and 60% in the most affluent states. Additionally, several cancers such as oesophagus, pancreas and lung have much poorer survival rates. This is compounded by often complex health needs due to the fact that people with cancer and (their caregivers) are frequently and increasingly elderly people with associated problems of co-morbidity.

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems such as fatigue, anorexia, nausea and constipation. Palliative care is not exclusive to cancer patients and also incorporates psychological and social care to patients and their loved ones throughout the course of the care process, including spiritual services that are tailored to the individual's personal beliefs and/or religious affiliation, especially in the context of end-of-life care.

## **2. Planning palliative and end-of-life care services: risk assessment, prioritisation, and goal setting**

### **Risk assessment**

There are marked differences in how palliative care services have developed in different states and regions of Europe. Services have been created in response to regional variations in health- and social-care structures. This has resulted in disparities in adopted definitions and implemented models and processes of care, within as well as between countries. However, there are some general principles that are widely applicable and that need to be considered during the planning and implementation phases:

- Needs assessment: development of palliative care services congruent with demonstrated need;
- Diversity of services (including bereavement support);
- Multi-disciplinary team approach;
- Wide exposure and opportunities for training in palliative care;
- Evaluation of services at the policy level;
- Clinical assessments at the patient level to assess outcomes;
- Investment for research in palliative and end-of-life care.

### **Prioritisation**

Establishing and demonstrating the need for palliative and end-of-life care services needs to focus on and capture information related to:

- The number that may need care (inclusive of trends and changing patterns for total cancer, site/type-specific incidence, prevalence and mortality in the population);
- The distribution of patients both in terms of geographical location as well as in terms of mode of residence (e.g. nursing and residential long-term care facilities) to ensure best possible access to both generic and specialist palliative care services;
- The scope and reach of the different care services modalities provided, including an assessment of the best professional mix required for the multi-disciplinary teams;
- The requirements in terms of amenities and resources such as rehabilitation facilities, medicines and medical devices.

## Setting objectives

The goal of palliative care is to improve the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end-of-life and bereavement (78).

The accessibility of relevant data can be challenging. The palliative care phase is often still outside “main stream” practices for guidelines and care management and in addition cancer registries do not typically include palliative care follow-up. Hence, mapping of palliative care requirements may also entail the inception, identification and consolidation of new and additional sources of information.

## 2. Programme elements

Palliative care services can be offered in a variety of settings and modalities. In general, a range of different services are needed in order to be able to meet the needs of different patients at the different phases of their cancer journey. The definitions and roles of the different services are ideally established and agreed between interacting groups of service providers. Planning for these services requires the assessment of the following conditions and factors:

### Aspects related to health system organisation

- The settings where palliative care services are provided: hospital-based (specialist/ general); hospice, community-based (home/residential/institutional e.g. nursing homes);
- The modalities of services offered in terms of whether they provide in-patient, day care, out-patient, home-based care or a combination of these modalities;
- Services that can be adapted to be more effective and specialised to deal with different and special groups of patients and circumstances such as with paediatric and adolescent/ young adult patients and people living in remote and rural areas. Female and male patients may require different services and approaches which in part may be related to the traditionally increased propensity for women to assume roles in family care, especially when there are health problems;
- Provision and coordination of integrated healthcare networks: coherent organisation of all service settings and modalities with the aims that care is truly multi-disciplinary, fragmentation is mitigated, efficiencies and cost-effectiveness of services is optimised and continuity of care is guaranteed.

## Resources

- Adequate availability of and accessibility for medicines (including opioids) and medical devices including those needed for the administration of these medicines outside healthcare facilities and equipment needed to help in the execution of activities for daily living (such as wheelchairs to aid mobility) and management of patients (such as hydraulic beds);
- Availability of human resources: in terms of quantity, diversity, competence and whether they are hospital- or community-based. This requires the consideration of issues such as recruitment, retention and the provision of opportunities for career progression of staff from a wide range of professions (health and non-health such as social workers) and specialised and/or generic training in palliative care, certification and continued professional development and assessment.

## Quality Assurance

This is often difficult to ascertain. However, there are a number of issues that must be considered. These include:

- Staff to patient ratios;
- Qualifications of staff in palliative care;
- Multi-professional teamwork; regularity of multi-professional case conferences; frequency of multi-professional visits or ward rounds;
- Use of standardized documentation systems;
- Availability of a 24-hr on-call service;
- Role and activity of volunteers/ voluntary organisations;
- Adequacy of cancer pain management and consumption rates of opioids.

## Emotional and spiritual support

This support emphasizes the critical roles of the psychologists, social workers, faith leaders and counsellors. The needs of patients, family and oncology staff should all be identified and managed within palliative and end-of-life care services.

Patients' needs include:

- Pain and symptom control and management of any functional changes;
- The quality of life for the patient;
- Emotional distress such as fears and anxiety;
- Psychiatric/ psychological, social and spiritual concerns;
- Any future wishes, the impact of loss and the challenge of facing impending death;

- Family needs may reflect issues similar to patients' concerns and will also include support during the process of bereavement;
- Support to staff working in oncology, palliative and end-of-life care services includes support offered to deal with any psychosocial stress manifestations and initiatives to strengthen competence, communication skills, self-awareness and group cohesiveness.

## **Legal and policy provisions and ethical issues**

These can include:

- The recognition of palliative care as a medical specialty;
- Incorporating palliative care provisions into the NCCP and other sectoral health plans;
- Social security entitlements for family caretakers (often women), who may have to leave the workforce to care for a dying relative;
- Decentralisation of services;
- Dealing with ethical dilemmas that may be related to how individual patients may wish to determine and choose how and when they will die.

## **Financing and sustainability issues**

The financing of palliative care services is highly diversified between and within Member States. The financial models in operation are often complex and include multiple sources. This situation further justifies the need for meticulous and long-term needs assessment, evaluation, planning and investment to ensure the adequate availability of the appropriate resources, the continuity of care and consequently the long-term sustainability of the palliative healthcare services.

## **Training in palliative and end-of-life care**

In most countries, training in palliative care needs a stronger presence in:

- Undergraduate and post-graduate curricula, and continued professional development programmes for all doctors, nurses and allied health care professions;
- The training of professionals working in the primary health care and community care services, particularly doctors in family medicine (general practitioners);
- The training of oncologists and other professionals working in regular and close contact with cancer patients. More specific and intense training in this field is required;
- Providing for opportunities for specialisation, employment and career development in the palliative care speciality. These specialists are essential

for the advancement of service standards and also for the provision of support to other professionals working with cancer patients especially in the community;

- The recognition of the role of volunteers and voluntary organisations. They often have important roles in increasing service provision and mobilising local support and community representation. It is important to ensure quality through careful selection, induction, training, supervision and support;
- Capacitating family caretakers to provide basic home care to relatives with cancer. These individuals have a crucial role to play in helping patients remain at home as much as possible, in guaranteeing a prompt medical or social response when required, and in preserving the psychosocial wellbeing of the patient (79).

### **Evaluation of services and clinical assessments**

Evaluation is needed to be able to:

- Compare and contrast provision of palliative care according to the different care modalities that are usually available in one geographical region;
- Ascertain the different outcomes that can be expected from the different service models and consequently the best categories of patients that can benefit from a particular service model;
- Help modify the scope of these services accordingly.

Policy-makers will use this knowledge for the planning and implementation of new palliative care services.

The clinical assessment of all cancer patients needs to include an appraisal of their palliative care needs. Appropriate assessment for patients needing palliative care should emphasize:

- Pain and symptom control;
- The quality of life for the patient inclusive of due consideration to patients' fears and anxiety and any future wishes;
- Psychological, social and spiritual concerns;
- The needs of family members and carers.

### **Investment in research**

The proportion of cancer research devoted to palliative and in particular for end-of-life care is known to be very low in most European countries. The NCCP needs to promote the prioritisation of research in the fields of palliative care therapies and needs for services. This promotion will be aided through the dissemination of the evaluation and assessment of outcomes (79).



## 4. Indicators

The following indicators can help policy makers monitor the comprehensive-ness, quality and effectiveness of the implementation of palliative and end-of-life care services (79). The feasibility of using any of these indicators needs to be assessed in terms of available sources and reliability of information and usability for external and internal comparability.

Types of Indicators	Core	Additional/Supplementary
<ul style="list-style-type: none"> <li>• Structure</li> </ul>	<ul style="list-style-type: none"> <li>• Distribution of facilities/ catchment area, types of services and locations where services are given</li> <li>• Doctor and nurse ratio per patient</li> </ul>	<ul style="list-style-type: none"> <li>• Inclusion of the palliative and end-of-life care in the NCCP</li> <li>• Proportion of funds for cancer research available for and used in the field of palliative, end-of-life care and bereavement support</li> </ul>
<ul style="list-style-type: none"> <li>• Process</li> </ul>	<ul style="list-style-type: none"> <li>• Place of death of cancer patients</li> <li>• Admissions/ referral to palliative care services especially in the last 1 year of life</li> <li>• Formal inclusion of palliative care as a medical and nursing speciality</li> <li>• Availability of services and resources for the special paediatric palliative care sector</li> <li>• Availability of 24-hour on-call service</li> <li>• National use of opioids in palliative care; annual number of patients treated, amount prescribed and dispensed, modality of delivery of opioids, list of indications for prescribing opioids. Description of the bureaucratic process for the prescription and dispensing of opioids for palliative care patients</li> </ul>	<ul style="list-style-type: none"> <li>• Epidemiological considerations inclusive of cancer incidence and mortality patterns (types of cancer, age at death, co-morbidity in cancer patients, time span from diagnosis to death)</li> <li>• Designation, availability, level of training and specialisation of the team members in the multi-professional teams</li> <li>• Availability of training in palliative care for social workers, psychologists, faith leaders and volunteers</li> <li>• Other training programmes in palliative care available. Level of education in which they are included and a description of training. Qualification and certification criteria applicable</li> <li>• Availability of the medicines and medical devices used in the practice of palliative and end-of-life care. Changes to approved medicines lists; trends in procurement, prescription and dispensing of these medicines, medical formulations and medical devices. Distribution of medical devices and medical equipment</li> <li>• Funding and financial models used for palliative and end-of-life care services</li> </ul>

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- |           |   |  |
|-----------|---|--|
| ● Outcome | ● Patient and family satisfaction indicators                                    | ● Availability, recruitment and retention of healthcare professionals specialising in palliative care services |
|           | ● Proportion of cancer patients dying within and outside health-care facilities |  |
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Acknowledgments: This chapter has been primarily guided by the following two sources: 78 and 79.

Part III.

# **Supportive Functions within the Health System**



# Governance and Financing

*Tit Albrecht, Antonio Federici*

## 1. Introduction

The World Bank defined governance as “the manner in which power is exercised in the management of a country’s economic and social resources for its development” (80).

Governance in health care is one of the key terms used by the World Health Organisation. It is more precisely defined as ‘a wide range of steering and rule-making related functions carried out by governments/decision-makers as they seek to achieve national health policy objectives that are conducive to universal health coverage. Governance is a political process that involves balancing competing influences and demands’. These include:

- Maintaining the strategic direction of policy development and implementation;
- Detecting and correcting undesirable trends and distortions;
- Articulating the case for health in national development;
- Regulating the behaviour of a wide range of actors - from healthcare financiers to healthcare providers;
- Establishing transparent and effective accountability mechanisms.

It is important to stress that governance in health does not imply only the management of resources within healthcare, but includes collaboration with other departments and agencies in the government and also with other sectors, such as the private sector and civil society, to promote and maintain population health in a participatory and inclusive manner. In countries that receive

significant amounts of external development assistance, governance should also be concerned with managing these resources in ways that promote national leadership, contribute to the achievement of agreed policy goals, and strengthen national health systems. While the scope for exercising governance functions is greatest at the national level, it also covers the steering role of regional and local authorities (81). This in particular applies to those countries where state administrative and political functions are strongly devolved and transferred to regional and local authorities.

### **Governance in cancer management**

Cancer management is one of the most complex disease management segments of healthcare. Given the broad scope and the multiple elements involving a great number of actors, governance in cancer is important for at least the following key reasons:

- Management and planning of all resources needed in healthcare for cancer management;
- Coordinate, nationally manage and sustainably finance comprehensive cancer services, including: screening, diagnosis, treatment and rehabilitation;
- Secure adequate level of knowledge about cancer for the population;
- Ensure stability of organisational support and financing of services supporting cancer patients beyond treatment and immediate oncological care.

## **2. Management and planning of cancer services and resources**

Given the complexities of cancer management today, planning of cancer services and resources should be carried out at different levels. Its base is established with the definition of a national cancer policy or strategy, which may coexist and either of which may be incorporated in the NCCP. At the national level, a thorough needs assessment needs to be carried out based on the current epidemiological situation, prospective needs based on epidemiological forecasting and on the developments in early diagnosis and treatment. This needs to be supplemented with the adequate follow-up in view of the rise in new technologies as a part of nationally established system of comprehensive health technology assessment, bearing in mind the national needs and also economic capacity to deal with the challenges of the modern oncological care.

Cancer services need to be coordinated nationally for the optimisation of all resources needed, but the specific organisation of oncological care delivery

has to be adapted to the specifics of the national health system for which the NCCP is being prepared. In order to meet the requirements of cancer care, this has to be organised in levels. Elements of a transparent organisation and planning of cancer services and resources:

- Designation of Comprehensive Cancer Centres (CCCs);
- A network of secondary cancer centres;
- Screening services for cancer – irrespective of whether they are adjoined to a secondary/tertiary network or if they are a part of primary care network;
- Structure and staffing of the centres with designation of training facilities;
- National capacity for adjuvant therapies;
- Financial resources allocated to cancer care and the respective services at all levels.

### **Planning and monitoring of the NCCP and its implementation**

- An integrated, comprehensive cancer control strategy allows for a more balanced, efficient and equitable use of limited resources;
- In order to plan cancer control wisely it is necessary to understand the context, appreciate past experiences, and be ready to continuously learn;
- A cancer control plan that is goal oriented, realistic and carefully prepared through a participatory process is more likely to move into effective implementation (82).

Similarly to any other structured and organised activity, an NCCP needs a sound monitoring system for its:

- a. Implementation;
- b. Follow-up;
- c. Updating and adapting;
- d. Base for the future development of cancer services at the national level.

Implementation of an NCCP may be more or less comprehensive, depending on its own structure and the breadth of services either restructured, newly introduced or depending on a broader health service reform context. Implementation of an NCCP needs to take into account the need to coordinate all key stakeholders in the health system – patients, health professionals, payers and policymakers. Securing leadership is essential in this sense and appointing the right institution or organisation for the process is necessary. Special attention in the implementation should be dedicated to those objectives that are common for proactive and population-oriented health systems – improving access to services and reducing socio-economic inequalities in cancer.

Follow-up provides insight into the level of achievement of goals and targets. This is especially relevant for structural and process indicators. However, there needs to be a system of updating and adapting the NCCP in place in order for the necessary changes to be included in the ongoing implementation and execution of the plan before it expires.

The experience of the current NCCP should feed into the preparation of the next NCCP, which needs to be prepared sufficiently ahead of time before the current programme ends.

### **3. Coordination, national management and sustainable financing of comprehensive cancer services**

The complexity of cancer requires a structured approach to the coordination of cancer services at all levels and for all types of cancer related care and disease management process. In a smaller member state, these tasks are best performed at a central location in close collaboration with the secondary and primary network of services. In a bigger or federal member state, devolution poses a challenge, where there is a need for national transparency of these services but at the same time it is required that services be coordinated and organised at regional, municipal and/or local level.

National policy may include:

- National Cancer Control Programme (NCCP);
- National strategy on cancer;
- Coordination of screening programmes;
- Evaluation of cancer services;
- International collaboration in the management of cancer patients and on research.

Financing of comprehensive cancer services should include the whole span of cancer management and control:

- Health promotion for cancer;
- Screening programmes and other secondary prevention programmes;
- Hospital and outpatient oncological care;
- Continued post-oncological care treatment and follow-up;
- Rehabilitation of cancer patients;
- Palliative cancer care;
- Financing of national and/or regional cancer registries;
- Financing of cancer research.



In some cases, international collaboration may be necessary to secure a high level of competent oncological care to patients. This is relevant in all cases when a country is short on resources for any type of cancer, any phase in its treatment and overall management or on research and its translation into practice. International exchange and referral to identified centres of reference and excellence may be not only necessary, but also practical in terms of both quality and costs. The 'EU Directive on cross-border care'(25) may have certain limitations to its practical application for cancer patients due to the complexity of cancer services. Hence, bilateral and multilateral collaboration is very important in this sense.

#### **4. Securing adequate knowledge about cancer for the population**

It is necessary to stress the importance of securing adequate levels of knowledge about cancer for the national population. This knowledge should be created using independent sources of information, and academic research provides an invaluable input. Efficient health promotion activities need to be carried out, adapted for the different age groups, thus extending the knowledge about cancer across generations. At this point, the NCCP should describe the use of health promotion campaigns, health education in schools and other activities, which target different generations in the society.

#### **5. Ensure stability of organisational support and financing of services supporting cancer patients beyond treatment and immediate oncological care**

Cancer is a disease that requires long-term planning, organisational support and sustainable financing for services, which should be designated as a public entitlement in order to secure their provision.

Patient pathways should also be defined outside of the pure and exclusive oncological care. They should include the following elements:

- Definition of patient pathways for all cancers and between levels of care;
- Arrangements required for the successful completion of the tasks at the primary care levels;
- Psycho-oncological support for the palliative and terminal care;
- Organisational support for the successful completion of all tasks on integrated cancer care.

6. Indicators

The governance function covers the monitoring of all indicators included in the other sections of this guide. The indicators below could supplement the other indicators as top-level policymaker levers.

Types of Indicators	Core	Additional/Supplementary
Structure	<ul style="list-style-type: none"><li>• Adopted National Cancer Plan/ Programme/Strategy</li><li>• Designation of responsible authority and leader for overseeing NCCP implementation</li></ul>	<ul style="list-style-type: none"><li>• Monitoring indicators for the implementation and execution of a NCCP</li><li>• A board or another body monitoring the implementation and development of actions according to the NCCP</li></ul>
Process	<ul style="list-style-type: none"><li>• Interim reports on progress towards implementation of the NCCP</li><li>• Allocation of ear-marked funds for all the activities introduced by the NCCP</li><li>• Explicit institutional links with HTA agencies and processes for adequate and speedy introduction of new diagnostic and therapeutic procedures</li><li>• Monitoring of the appropriateness of allocation of resources for the individual actions of the NCCP</li></ul>	<ul style="list-style-type: none"><li>• Epidemiological considerations inclusive of cancer incidence and mortality patterns (types of cancer, age at death, co-morbidity in cancer patients, time span from diagnosis to death</li><li>• Designation, availability, level of training and specialisation of the team members in the multi-professional teams.</li><li>• Availability of training in cancer care for social workers, psychologists, faith leaders and volunteers.</li></ul>
Outcome	<ul style="list-style-type: none"><li>• Registries to support the NCCP implementation with epidemiological data</li><li>• Outcomes of screening programmes</li><li>• Outcomes of other newly introduced services and actions according to the new NCCP</li></ul>	<ul style="list-style-type: none"><li>• Availability, recruitment and retention of healthcare professionals specialising in cancer care services</li></ul>

# Cancer Resources

*Regine Kiasuwa, Saskia Van den Bogaert, Marc Van den Bulcke*

## Background

The development of proper institutional and professional capacity is a challenge which takes time, and strategic planning needs to be forward-looking. Planning for institutional, human, technological and financial resources needs to follow a comprehensive approach, with regular examination of changes in the demand and supply of cancer care in order to ensure the continued delivery of high quality services. If challenges such as shortages and inadequate access emerge, timely and flexible policy actions need to foresee to resolve them.

Within the overall setup of a national cancer plan, ‘coordinated care’ represents the fundamental organisational premise of such plan. The necessary assets to support a national cancer plan need to be defined, financially-supported and guaranteed in line with the overall health policy of the government(s). The issues discussed below in this chapter should be considered in close liaison with the chapter on governance.

Hereafter, a number of important items related to the ‘economics’ of national cancer plans are itemized covering in particular Human resources, Infrastructure, Health technology and Cancer Specific Expenditure (83, 84).

## 1. Human resources

Although general practitioners may play a key role in identifying the early symptoms of cancer development, most cancer care will be concentrated in specialised centres such as general hospitals. NCCP planners must first evaluate their cancer care workforce (including general physicians, nurses, pathologists,

specialists in radiation, surgical and medical oncology, social workers, psycho-oncologists, pharmacists, palliative care specialists and administrative support staff, among others) to better understand where shortages or surpluses exist, and adapt health workforce planning according to the following considerations:

- Targets delineated in the NCCP;
- Projected cancer burden according to demographic and epidemiologic indicators;
- Health workforce characteristics (age, sector/specialty, workload requirements, productivity).

### **Training, education and certification**

For high quality cancer care, several provisions need to be in place to ensure that professionals are well-prepared:

- Licensing and certification systems;
- Degree programmes for high-priority medical specialties, including one or more university or departmental chairs;
- Continuing education programmes related to oncological care, for both general and specialist physicians, nurses and medical support staff;
- Inclusion of integrated care principles within medical curricula;
- Specific requirement for a module on patient communication for all staff working with cancer patients, in addition to clinical coursework.

### **Effective number and distribution of specialists**

Globally, there is a deficit in qualified health professionals, and cancer services do not constitute an exception. Medical migration, either from rural to urban areas, or from poorer to richer countries, constitutes a major issue, especially considering that EU Member States are at a crossroads between source countries in Asia and Africa, and other destinations within the EU or in other developed countries such as the USA. The WHO Global Code of Practice sets out guidelines to help countries secure an adequate workforce for their populations. These principles also apply to the specific area of cancer control:

- Pairing of population needs and workforce supply, through coordination with universities and other learning centres that offer certification or licensing of medical professionals;
- Increased education and training for health sector students;
- Improved conditions for healthcare professionals;
- Continued medical training and increased opportunities;

- Incentives to retain physicians and nurses in countries and regions with human resource shortages;
- Ethical recruitment practices;
- Protection of the rights of foreign healthcare workers.

### **Other professionals in the health sector**

In addition to clinical and training staff, cancer control activities require a large supportive workforce for functions that include the following:

- Record-keeping, including cancer registration;
- Screening recruitment and follow-up;
- Communication in health promotion and prevention;
- IT support;
- Social work;
- Quality assurance audits;
- Service coordination;
- Health Technology Assessment (HTA).

## **2. Infrastructure**

### **Healthcare settings**

Cancer-related health services may be offered in a wide variety of health centres. The precise configuration of these will depend on many factors, including the presence of existing centres, the distribution of the population, and the availability of resources. In general, services may be offered in the following settings:

- Hospitals;
- Comprehensive cancer centres (CCCs);
- Primary care facilities;
- Specialised out-patient facilities;
- Mobile units (for home care or rural service provision);
- Nursing homes, residences and/or hospices.

### **Access and geographic distribution**

With regards to infrastructure for cancer-related health services, inadequate access, long waiting lists or distance to institutions that treat cancer are often a major challenge. On the one hand, the costs and shortages associated with

state-of-the-art equipment and experts seem to advise the centralisation of services in CCCs; on the other, in countries with largely dispersed populations, this modality could limit access for patients. These difficulties are also relevant for patients with rare cancers, as specialists tend to be few and far between.

Different solutions to this dilemma have been explored and include:

- *Mobile units for screening, treatment and palliative care.* Mammography, radiology, chemotherapy and palliative care have all been offered in mobile units, which bring scarce expertise and expensive equipment to underserved areas;
- *Regional cancer networks.* Whether specialists from regional hospitals travel to rural areas to see patients, or multidisciplinary teams are formed through virtual connections and shared access to electronic medical records, the network approach stands out as a way to increase access to specialist care for rural populations. European networks have also begun to develop as the field of rare cancers, which individual countries may not be able to effectively address alone;
- *eHealth tools.* For cancer prevention, management, rehabilitation and palliative care, access to eHealth tools may provide a low-cost way to provide patients with tailored information, support and advice. They may also be used to provide continuous education and upskilling to dispersed health professionals. Tools include telemedicine, SMS messaging, smartphone applications and social media support networks, among others;
- *Twinning.* CCCs may establish bi-lateral relationships with general hospitals or outpatient centres in order to provide laboratory resources or specialist expertise to other health centres or services;
- *Cross-border collaboration.* Small countries and geographic regions sharing borders may find it beneficial to pursue cross-border collaborations for more efficient healthcare provision, for example through jointly funded general hospitals or cancer centres to serve rural populations on both sides of the border.

### Quality assurance

Quality assurance (QA) programmes seek to ensure that the healthcare provided meets certain standards of care. A mix of methods is used, usually requiring the following non-human resources:

- Service vehicles for on-site inspections of cancer centres;
- Audit report forms;
- Access to hospital records and other patient data;
- A Health Technology Assessment (HTA) unit.

### 3. Health technology

Health technology is a major driver of increasing costs in cancer services, challenging the cost-effectiveness balance. HTA supports decision-makers by promoting the rational use of medicines and evidence-based cancer care, but it is quite expensive to carry out; cross-country collaboration has great potential benefits, particularly with regard to assessing breakthroughs in diagnostic and clinical care (85).

#### Equipment

The availability of diagnostic and clinical resources for cancer services is uneven in many countries, with higher concentrations and overuse in some areas and discouraging shortages in others. To date, few policy responses to the increase in diagnostic equipment and services have been implemented. The authorisation process for medical devices and the planning and monitoring of their supply and distribution is an important requisite. At the EU level, the regulation on medical devices will be a very important step forward in this respect (86).

Listing all technology implied in cancer care is out of the scope of this document but according to the scope of the provided care, the institution should have access to all necessary technology to safe-guard optimal care of the patient. Core technologies required for cancer control would be:

- Availability of radiotherapy;
- Availability of a cancer surgery facility;
- Availability of a mammography unit;
- Availability of a 'Magnetic Resonance Imaging' (MRI) facility;
- Availability of a 'Computer tomography' (CT) scanning facility;
- Availability of a 'Positron emission tomography' (PET) scanning facility;
- Availability of a (advanced) immunological and molecular analysis facility;
- Experience with chemotherapy including the use of innovative cancer drugs;
- Laboratory units to support screening, diagnosis and treatment needs.

#### Cancer therapy

The main objective with respect to a cancer drugs and therapy is to ensure prompt access to the best cancer treatment in an acceptable way for patients and the government, but also for the pharmaceutical and health technology industry, which will be responsible for much of the research investment that

leads to innovative therapies. Clear ground rules, transparent and participatory processes, rigorous and continuous assessment, and administrative consolidation are the keys to improving access to innovative therapies for cancer patients. The European Medicines Agency (EMA) is responsible for the scientific evaluation of medicines. Once granted by the European Commission, the centralised marketing authorisation is valid in all EU Member States, as well as in the European Economic Area (EEA) countries (87).

However, Member States usually have a separate process to decide whether new drugs will be covered by public funds; this process can last anywhere from a few months to several years, involving different agencies and ministries, which sometimes must negotiate with multinational pharmaceutical companies and conduct studies on cost-effectiveness in a national setting. The differences between Member States lead to pronounced inequities in access to innovative drugs, exposing a clear need for EU cooperation and leadership.

In developing an NCCP, health systems should work on different levels to improve decision-making and access to innovative drugs and health technology:

- First, planners must evaluate the current approval process for inclusion of new technologies to reduce bureaucratic bottlenecks, consolidate responsibilities, and identify areas in which greater participation from scientific advisors and patients would be desirable;
- The criteria used for deciding whether a new drug should be included in the public system should be defined for all stakeholders, including patients and the pharmaceutical industry. These may include a variety related to efficacy, efficiency, equity and quality;
- The Ministry of Health should work with research centres and the pharmaceutical industry to identify research priorities in line with the present and projected disease burden;
- It should also work together with universities, research centres, patient associations and the pharmaceutical industry to revise the process for inclusion in clinical trials and to expand access to experimental drugs for dying patients (compassionate access). In light of recent advances in genomics and personalised medicine, it is particularly important to be able to quickly pair innovative and experimental drugs with patients who could potentially benefit from them;
- In parallel, Ministries of Health may seek synergies and cooperation with their counterparts in other countries and at an EU level to identify potential areas of cooperation, such as cost-effectiveness analyses or joint procurement of pharmaceuticals, which could save money.

## Assessment

A process of continuous health technology assessment should be set up as soon as new health technology is included within the public healthcare system.



Benefits of health-outcomes data for cost-effectiveness analysis include the following:

- Estimates of effectiveness (effect of drug in real-world setting) rather than efficacy (effect of drug in ideal or highly controlled setting) in a variety of typical practice settings;
- Comparison of several alternative interventions (e.g., older versus newer drugs) or clinical strategies to inform choice of optimum therapy beyond placebo comparators;
- Estimates of the evolving risk-benefit profile of a new intervention, including long-term (and rare) clinical benefits and harms;
- Examination of clinical outcomes in a diverse study population that reflects the range and distribution of patients seen in clinical practice;
- Results on a broader range of outcomes (e.g., patient-reported outcomes, quality of life, and symptoms);
- Data on resource use for the costing of health-care services and economic evaluation;
- Information on how a product is dosed and applied in clinical practice and on levels of compliance and adherence to therapy;
- Data in situations where it is not possible to do Randomized Clinical Trials (RCT);
- Substantiation of data collected in more controlled settings;
- Data in circumstances where there is an urgency to provide reimbursement for some therapies because it is the only therapy available and may be life-saving;
- Interim evidence—in the absence of RCT data—upon which preliminary decisions can be made;
- Data on the net effects of clinical, economic, and patient-reported outcomes after implementation of coverage or payment policies, or other health management programmes.

Within the NCCP, measures could be taken in order to improve the rational use of medicine, by for example, applying cost-effectiveness principles through the HTA or organising clinical monitoring. NCCPs should also ensure a follow up of the availability and the speed of uptake to support authorities providing precious information about the implementation of decisions.

NCCPs activities should be able to report the improvements, the gaps, the remaining difficulties in terms of access, efficacy and cost-effectiveness of medicine used for cancer care.

## 4. Cancer-specific expenditure

Expenditures for cancer control are extremely complex to calculate as very often, they are integrated in institutions or structures that are not dedicated to cancer only (disease prevention, palliative care, dependence care, surgical units, etc.). Some expenditures, though, are specifically related to cancer:

- Population-based cancer registries and cancer-related information systems;
- Cancer drugs;
- Secondary prevention;
- Cancer research;
- Oncological care, including psycho-oncology;
- Long-term rehabilitation care, including:
  - Physical revalidation;
  - Reconstructive surgery;
  - Occupational/vocational therapy;
  - Psychological support/therapy (family or couple therapies);
  - Social care (home nursing and social assistance);
  - Cognitive therapy (training for self-management);
- Management, follow-up and evaluation of the NCCP itself;

In addition, the budgeting process should take into account the following considerations:

- Innovative breakthroughs that may not exist at the time the budget is implemented;
- Recent advances in the molecular analysis of cancer biology at the genome level, which will require major investments in technical expertise and infrastructure to facilitate the exchange of 'big data' information files;

Some possible solutions to the specific issues of financing cancer control are presented below:

- Ensure stratified and targeted cancer medicines are equitably available to patients;
- Recognise that these medicines require an appropriately funded approach to fair reimbursement and pricing;
- Identify cancer service related savings for use on cancer medicines and other cost-effective interventions;
- Re-engineer chemotherapy suites to assure optimised and efficient usage, and purchase high-quality off-patent medicines efficiently;
- Ensure continued inward investment into countries by life-sciences companies;

- Develop life-sciences strategies with strong promotion of low clinical bureaucracy clinical trials;
- Where possible, move cancer care out of hospital to lower cost and safer settings;
- Optimise use of oral and other cancer medicines that allow patients to be treated safely at home or in other community settings;
- Reduce limitations and uncertainties in cancer-medicines evidence-base;
- Investigate use of risk share and flexible pricing arrangements with payers.

## 5. Indicators

The horizontal nature of questions related to cancer resources does not lend itself to the development of indicators that help monitor roll-out and implementation of specific programmes; in general, all indicators fall into the category of “structural”. Below, possible indicators are included for the resources in the categories detailed above. **Targets for all indicators related to cancer resources should be adjusted in light of the targets for vertical programmes in the NCCP, and vice-versa.**

Fields	Core	Additional/ Supplementary
Human resources	<ul style="list-style-type: none"> <li>• Existence of a written, needs-based plan or strategy for building and maintaining human resource capacity in cancer control, according to priorities delineated in NCCP, considering:</li> <li>• Needs-based assessment based on epidemiologic and demographic indicators, and current workforce characteristics (age, sector/specialty, workload and productivity)</li> <li>• Undergraduate, graduate, and continuing training; licensing and certification</li> <li>• Worker retention, especially for high-priority disciplines, disciplines where shortages may exist, and for underserved areas</li> <li>• Administrative and supportive functions</li> <li>• Ethical recruitment standards and practices</li> </ul>	<ul style="list-style-type: none"> <li>• Network approaches for areas in which human resource shortages currently exist</li> </ul>
Infrastructure	<ul style="list-style-type: none"> <li>• Comprehensive treatment centres per 100,000 people.</li> <li>• Cancer surgery facilities per million people</li> <li>• Hospital beds for oncology and palliative care, per million population</li> <li>• Average distance to a cancer treatment facility for rural and urban populations</li> <li>• Average waiting time for cancer surgery</li> </ul>	<ul style="list-style-type: none"> <li>• Mobile screening, treatment and/or palliative care units per 100,000 rural population</li> <li>• Implementation of any specific strategies to address problems accessing cancer care facilities, including transport, telemedicine, cross-border agreements, or others</li> </ul>
Technology	<ul style="list-style-type: none"> <li>• Radiotherapy units per million people</li> <li>• Mammography unit per million people</li> <li>• 'Nuclear Magnetic Resonance' facilities per million people</li> <li>• Computer tomography (CT) scanner units per million people and GDP</li> <li>• Positron emission tomography (PET) scanners per million people</li> <li>• Immunological and molecular analysis facilities per million people</li> <li>• Number of laboratory units to support screening, diagnosis and treatment needs</li> </ul>	

Cancer therapy	<ul style="list-style-type: none"> <li>• Existence of clear ground rules and transparent criteria for decision-making related to reimbursement for new cancer drugs, considering equity a key criteria</li> <li>• Absence of co-payments for essential drugs</li> <li>• Existence of a specific strategy to foster health technology and translational cancer research, including an explicit list of research priorities and provisions to increase recruitment of patients to clinical trials</li> </ul>	<ul style="list-style-type: none"> <li>• Average time for uptake of new cancer drugs in national health portfolio following approval by EMA</li> </ul>
Can-cer-specific expenditure	<ul style="list-style-type: none"> <li>• Budget lines for cancer expenditure in the following areas:</li> <li>• NCCP coordination and management</li> <li>• Cancer registries and cancer-related information systems, including investments in technology to facilitate exchange of 'big data' files</li> <li>• Secondary prevention</li> <li>• Cancer research</li> <li>• Oncological care, including psycho-oncology</li> <li>• Long-term rehabilitation care</li> <li>• Cancer innovation (a flexible line item to expedite uptake of life-saving cancer therapies which may not exist at the time of NCCP adoption)</li> </ul>	<ul style="list-style-type: none"> <li>• Additional, cross-cutting resources in other areas related to cancer control, including:</li> <li>• Primary and non-oncological specialised care, including nursing</li> <li>• Health communication and education</li> <li>• Palliative care</li> <li>• Social support services</li> <li>• Hospital expenditure</li> <li>• Health administration</li> </ul>



# Cancer data and information

*Fiona Conroy*

## 1. Background

Cancer information is an important tool in helping to reduce the risk of cancer in the entire population and to improve outcomes for people diagnosed with cancer. Availability and access to high-quality, comprehensive data on cancer-related indicators is essential for evaluating the efficacy of cancer prevention, screening and control, monitoring cancer risk, improving patient safety, monitoring care and treatment and managing resources related to the delivery of health and personal social services for people with cancer. A wide range of information may be relevant to these objectives. Reducing cancer risk requires information on both the causes of cancer (aetiology) and their prevalence in the population (epidemiology). These may include patient characteristics, cancer characteristics and environmental factors. Evaluation of patient care requires information on the timing, appropriateness and quality of treatment, aftercare and support, and patient compliance with treatment.

Information in these areas may come from many sources. For cancer risk, it primarily comes from official statistics and community surveys; for cancer services, the primary source is cancer registries, linked to prescribing data, hospital administrative data, patient surveys and other data sources. Population based cancer registries are essential in providing objective and standardised information on both risk factors and their impact on cancer incidence; and on patterns of care and outcomes of cancer patients. Linkage of all sources to a central register of cancer patients is essential if their value is to be maximised. Registration of cancer at population level can identify trends in cancer that will enable researchers to generate hypotheses and address questions about the

findings and can help refine our understanding of how the cancer burden will evolve over time. Population-based cancer registries can also facilitate research and the planning and management of cancer services—to answer questions about cancer causation, prevention, treatment and control, to locate geographic areas with higher than average rates of cancer, to study patterns and outcomes of cancer care, to estimate the cost of cancer, and to identify risk groups for research and intervention programmes. Analysis of this data can provide information to service planners, providers, policy makers and clinicians and is also a key tool in the delivery of best possible outcomes for patients.

Patient and public involvement in cancer registries is also of paramount importance, as it helps to engage patients when setting research priorities and in conducting the research itself. Proper dissemination of registry data (with appropriate privacy protections) is also an important tool for accountability.

Access to a registry can also facilitate case-control, cohort and randomised control research into cancer aetiology and outcomes.

## 2. Data sources

### Cancer registries

National cancer registries constitute the backbone of a cancer information system, tracking the incidence, prevalence, mortality, survival and patterns of care for all cancers. There are two main types of cancer registries:

- *Population-based registries* collect data on all new cases of cancer occurring in a well-defined population in specific geographical areas; which provide extremely valuable information that can be used for comparative purposes (88);
- *Hospital-based registries* constitute a fundamental tool to monitor quality of care within a hospital.

A number of issues must be resolved by planners in setting up, improving or expanding their cancer registries. Logically, the more data collected, the stronger the evidence base that users will have to work with, but resource limitations may initially limit the most comprehensive data collection. However, if appropriate structures are put into place at the start, expansion of the registry at a later date will be facilitated.

Likewise, a good quality national registry in line with international standards (principally the most current version of the International Classification of Diseases, or ICD (89) can facilitate registry linkages across national borders. The EPAAC Joint Action, as well as the European Commission's Joint Research Centre, have taken important strides towards creating a united European



Cancer Information System (ECIS), with huge potential for optimising the use of cancer data throughout the EU (90).

### **Population data sources**

Many other sources of data on population health exist. Particularly in the case of evaluating the prevalence of behavioural or environmental risk factors in a population, studies are generally carried out on anonymous samples and can be usefully linked with other data sources such as cancer registries. Data may be available from administrative and taxation databases on tobacco and alcohol consumption, or from health interview surveys, such as the European Health Interview Survey (EHIS) modules coordinated by EUROSTAT. The EHIS tracks major risk factors in the population, and can provide clues about future cancer incidence well into the future (for example, by examining smoking prevalence among young people). Other disease registries, on the other hand, are not anonymised. If these data are properly linked to cancer registries through a Unique Patient Identifier (UPI), they can help elucidate the risk of co-morbidity between cancer and other diseases or conditions, such as those with HIV, organ transplant recipients or others.

## **3. Organisational considerations**

### **Population**

The geographic or administrative area to be covered should be defined.

### **Legal provisions**

An adequate legal framework must support the functioning of the cancer registry:

- Mandating collection of cancer information for registry purposes;
- Ensuring privacy, confidentiality, and data protection, on the one hand, while at the same time offering well founded access for policymakers, researchers, clinicians, and citizens, on the other;
- Linking the cancer registry with other population-based data sources or disease registries, either at a national or international level;
- Regulating the terms of data ownership and control.

## Methods of registration

### *Coding, classification and quality*

- A standard classification method (WHO expects Member States to use the most updated version of the International Classification of Diseases; the version for oncology, ICD-O-3, is generally used by registries) should be used to facilitate comparison and contrast of information over time and between populations, with provisions for adapting data from previous versions of the tool (89);
- International guidelines on classification and coding, as published by the International Agency for Research on Cancer (IARC), International Association of Cancer Registries (IACR) and European Network of Cancer Registries (ENCR) (91) and by UICC for staging, should be used whenever applicable;
- A UPI should be used by the registry; this should be the same as those used by other disease registries and (where possible) population health surveys in order to facilitate linkage;
- Data quality assurance should be added as an important point.

## Links with other data sources

Linkage with other sources of data is crucial to deepen scientific understanding of how and why cancer develops, as well as risk factors and common comorbidities. The UPI should allow a safe and confidential way to cross-check cancer incidence with the incidence of other diseases and risk factors or simply the life status of cases. Cancer registries can be linked with other data in two ways:

- Linkage with sources of routine data such as prescribing data, death certificates and hospital administration data in order to complete a cancer registration;
- Incorporation of cancer registry data into a larger cancer information database which may include information on non-cancer patients, e.g., biobanks, familial disease registers, screening databases, waiting times data and other information relevant to planning and monitoring cancer services.

The use of a UPI can reduce the technical, legal or resource obstacles to linkage.

Links should also be established between national cancer registries and international databases, including other disease registries related to cancer, such as the European Platform for rare disease registries, which is currently being established by the Joint Research Centre. The International Agency for Research on Cancer (IARC) has traditionally gathered information arising from population-based registries, compiling the publication “Cancer Incidence in Five Continents” (periodically updated). A number of organisations, including

the European Commission's Joint Research Centre, the European Network of Cancer Registries, EURO CARE (European cancer registry based study on survival care of cancer patients) and the European Cancer Observatory have all taken action to move towards a shared platform for cancer data and information. Given the promise for large epidemiologic studies on cancer trends - and the potential to achieve a critical mass of data for rare cancers, individual countries have much to gain through cooperation and contribution to these initiatives.

## 4. Outputs

There are several considerations that must be made with regard to the data itself, relating to the indicators sought and the methodology of data collection. Specifically, planners must ensure that the cancer registry collects the data that programme managers need to evaluate the fulfilment of the targets delineated in the NCCP. Cancer registries should be able to provide information on the following, disaggregated by age, sex and cancer type; other socio-demographic indicators such as region of residence, ethnicity and socioeconomic group may be added as relevant to the local situation:

- Cancer incidence, trends and projections;
- Cancer prevalence, trends and projections;
- Cancer mortality rates, trends, projections and person-years of life lost due to cancer;
- Relative survival rates, trends and projections;
- Course of treatment;
- Survival;
- Stage at diagnosis.

A range of other indicators may also be available from registries; these may include direct and indirect costs of care, quality of life, patient experience of care and access to services such as counselling, prostheses and palliative care. Many of these are not suitable for routine collection for all patients but may be registered for either random or selected sub-groups.

## 5. Registry quality indicators

Some aspects of registration which may be monitored in order to better understand the quality of the registration are summarised in the following table:

Types of Indicators	Core	Additional/ supplementary
Structural	<ul style="list-style-type: none"><li>● Percentage of target population covered by cancer registries</li><li>● Adequacy of human, financial and technical resources to support core registry activities, including data collection, quality assurance and dissemination</li><li>● Number of core registration items collected by the registry; a full list of core items for European registries, as agreed by the ENCR, is given in <a href="http://www.encr.eu/images/docs/recommendations/recommendations.pdf">http://www.encr.eu/images/docs/recommendations/recommendations.pdf</a></li></ul>	
Process	<ul style="list-style-type: none"><li>● Timeliness of ascertainment and reporting</li><li>● Regular quality assurance to ensure quality and international comparability of data (in line with IARC and ENCR guidelines ) e.g. percentage of cases missing essential demographic information such as age and sex; percentage of cases with unknown site and/or morphology; percentage of death certificate only cases; percentage of histologically verified cases. Acceptance of the data by IARC for “cancer Incidence in Five Continents” is a useful benchmark of the international comparability of the data</li><li>● Completeness of ascertainment of cases, as assessed by quantitative methods</li></ul>	
Outcome	<ul style="list-style-type: none"><li>● Clinical data available (stage, treatment, diagnostic procedures)</li><li>● Completeness of follow-up of all cases to date of death</li></ul>	<ul style="list-style-type: none"><li>● Compliance with all legal and administrative obligations with regard to data confidentiality and security</li></ul>

# Research

*Tit Albrecht, Marjetka Jelenc, Jose M. Martin-Moreno*

## 1. Background

Cancer research is one of the cornerstones of overall cancer management, but also one of the most difficult to effectively characterise or manage due to the multiplicity of independent and interacting players that fund and perform the research. Public bodies at a Member State, European and international level; private industry; universities and research centres; charities and NGOs all take part to some degree in cancer research, with overlapping or duplication of efforts in some areas and scarce research activity in others. Coordination between research bodies and funders, then, is a major priority and a challenging goal (92). Some initiatives in this direction have already been completed (such as Eurocan+Plus), while others are still ongoing (including ERA-NET and TRANSCAN) (93, 94).

Other major elements of a national cancer research agenda include aligning investments with policy priorities and needs from the citizens/patients' perspective; ensuring a regulatory framework that facilitates access and linkages to data for researchers; increasing the participation of patients, both in development of the research agenda and involvement in clinical trials and other studies; and pursuing cross-border collaborations where European added value is perceived (95).

## 2. Developing the national cancer research agenda

### **Assessment of the national cancer research panorama**

The first step in developing a national cancer research agenda is to understand what research is already being performed and who is paying for it. At

a European level, certainly, a comprehensive evaluation has proved elusive; funding comes from a number of different sources, many of them private, and generally there is no obligation to report activities to a central body to keep a record of what activities are taking place. Moreover, the use of clinical instruments and materials for research within the healthcare system is not always properly accounted for where there are research funds used for healthcare purposes. All in all, we lack “sensitivity” and “specificity” when assessing resources allocated for research, and this is a very common problem.

However, this information is of extreme value to health authorities that wish to identify duplications and gaps in research objectives. Specifically, efforts should be made to characterise (insofar as it is feasible) the research activity from the following actors:

- International health organisations (IARC, WHO, World Bank, OECD, etc.);
- Research initiatives funded by the European Commission;
- Public and private universities or other national research centres;
- Governmental ministries (often, health research is also conducted by ministries of science, research and development, industry and others);
- Scientific and professional societies (such as EORTC, ESMO, etc);
- Health technology industry;
- Charities and NGOs.

By mapping current research activity in terms of objectives and funding, national planners can better understand where further public support is needed and where increased coordination would be desirable.

### **Prioritisation of national research priorities**

In consultation with scientific advisors, patient groups, other governmental bodies, industry representatives, and the NCCP coordinating body, research priorities should be set according to national cancer policy goals, and adjusted according to ongoing activities at an international level. Some research findings in one country can easily be translated to another setting, while others must necessarily be context-specific. Likewise, pooling data from various countries can afford researchers a more comprehensive view of other key research problems.

Areas where a greater degree of European coordination could achieve the most added value include some of the following:

- *Basic and clinical research.* Because these research results are directly translatable to all settings (i.e., they are not context-specific), Member States can benefit from a concerted approach. This area includes research

on cancer therapies, genomics, pain management, diagnostic technologies and procedures, and others;

- *Epidemiology and public health research.* The heterogeneity of the European population, in terms of health-related behaviour, demographics and health and social systems is fertile ground for epidemiologic research. Analysis of large data sets can potentially shed much light on cancer epidemiology and different health policies aimed at reducing the cancer burden;
- *Outcomes research.* The specific objectives of cancer outcomes research are to describe, interpret and predict the impact of interventions and other factors (socioeconomic, organisations, technological and behavioural) on final outcomes. Thus, analysis of data across Europe can yield important information which may help speed up the application of novel products, tools and approaches in healthcare systems;
- *Research on rare and paediatric cancers.* Because the incidence of rare cancers is, by definition, quite low, individual Member States can often not obtain the critical mass and statistical power necessary to understand the causes or the best treatment pathways to address these diseases. The ability to draw on data from a population pool of over 500 million inhabitants would be immensely useful.

On the other hand, national research may be somewhat preferable in areas that are strongly influenced by health system organisation and cultural norms, although the benchmarking approach and European dimension can also be a focus within these fields. A few of these areas include the following:

- Health systems and health services management;
- Psycho-oncology and social support;
- Health communication;
- Health promotion.

When deciding on national objectives for cancer research, and especially in settings where few resources are available for cancer research, NCCP planners should first prioritise areas that depend on a local context, while also taking steps to make use of research findings from other countries that can improve cancer control at home. Literature reviews or clinical practice guidelines that draw on international sources but are written in local languages could be a useful way to disseminate knowledge on a national scale.

## Coordination of cancer research

Once health authorities have mapped ongoing research activities and can contrast this information with the national priorities set out after consultation with key stakeholders, strategies for increased coordination can be developed. As noted by the Research Work Package in the European Partnership

for Action Against Cancer (EPAAC), there is no “one-size-fits-all” approach to cancer research coordination; rather, initiatives must be tailored to specific disciplines and groups of actors. During EPAAC, pilot projects were proposed in the areas of early phase clinical research in personalised medicine, cancer outcomes research, and epidemiology in public health; these could constitute useful models for other coordination activities at a Member State or European level.

Indeed, one relatively efficient way for countries to foster cancer research coordination is to strongly support the Commission’s efforts to do so at a European level in order to facilitate the necessary critical mass and uphold high efficiency of resources. Given the scarcity of financial, human and information resources for cancer research, a top-down approach, beginning at an international level and in close collaboration with the scientific community, is a sensible way to begin to optimise resource use. The European Commission has a major role to play in coordinating cancer research at EU level, and all available instruments should be used to bring funders and scientists together, and to stimulate academia/industry partnerships. Existing limitations should be addressed by bringing together the scientific community with Member States and Associated Countries, NGOs, industry and other stakeholders in the cancer research continuum, with the aim of developing a concerted approach to achieve coordination of research from all funding sources within selected areas of cancer research.

At a national level, health authorities can also take other actions to foster coordination of cancer research funding:

- Consideration of European and international research activities when allocating cancer research resources;
- Periodic consultation between policymakers, patients, industry and researchers to revise research objectives in light of policy needs (always keeping in mind the best interest for citizens in general, and patients in particular), and vice versa;
- Promotion of public-private partnerships with ethical, transparent ground rules for collaboration;
- Centralised platform to access research data and findings;
- Awarding of public grants to support non-profit research objectives in line with cancer research agenda;
- Alignment of all governmental sources of cancer research funding.



### 3. Regulatory framework

Access to population data is a vital resource for cancer researchers, so an important part of fostering cancer research at a national level is to ensure that the regulatory framework is conducive to research activities. This can be done through two channels:

- *Advocacy on a European level* for sensible data protection controls, which ensure the legitimate privacy for individual patients without unduly burdening researchers with costly or time-consuming administrative requirements;
- *Revision of data protection laws at a national level.* The current European Data Protection Directive has been interpreted by Member States in different ways, meaning that researchers in different countries are bound in varying ways by data protection laws. Scientific advisors and researchers should have the opportunity to share their perspective on how national data protection laws help or hinder their work, with legislative amendments implemented as appropriate and when feasible.

### 4. Research investment

Once a national cancer research agenda has been set with the participation of all main stakeholders, and a regulatory framework is in place to facilitate research activities, ministries of health will be in a better position to understand where funding is most needed. The exact amount of public research funding will depend on resource availability, but a minimal level is required, at least to manage information systems and to monitor ongoing cancer programmes. Only through periodic evaluation of process and outcome indicators can policymakers understand how effective an NCCP is.

### 5. Patient participation

Cancer control is undergoing an important shift in decision-making and practice due to the growing role of patients and patient advocates; cancer research is no exception. Patient involvement in cancer research may be fostered through any number of measures and settings, for example:

- Participation in research agenda setting, to ensure that policy priorities are in line with patients' priorities;
- Increased interaction with patients in research fields (such as palliative care, survivorship, psycho-oncology or rare diseases) in which patient experiences have the most potential to enrich findings;

- Close involvement in quality-of-life research;
- Increased access to - and involvement in - clinical trials;
- Fundraising and advocacy.

6. Indicators

Types of indicators	Core	Additional/ Supplementary
<ul style="list-style-type: none"><li>• Structure</li></ul>	<ul style="list-style-type: none"><li>• Accounting systems to properly identify resources allocated to research</li><li>• Sources of public financing of cancer research (budgets from Ministry of Health, Ministry of Science, other Ministries; Health Insurance)</li><li>• Per capita expenditure on cancer research</li><li>• Number of researchers</li><li>• Number of research centers</li></ul>	<ul style="list-style-type: none"><li>• Total expenditure on cancer research in the country – in EUR (apart from the national currency if other)</li><li>• Share of public financing in total expenditure on cancer research</li><li>• Share of total expenditure of cancer research in total research expenditure at the national level</li></ul>
<ul style="list-style-type: none"><li>• Process</li></ul>	<ul style="list-style-type: none"><li>• Number of new and ongoing research projects (medical and translational)</li><li>• Evidence of involvement of patients in clinical research</li></ul>	
<ul style="list-style-type: none"><li>• Outcome</li></ul>	<ul style="list-style-type: none"><li>• Evidence of improved research outcomes in the field of cancer (96)</li></ul>	

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