

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

Tit Albreht, Régine Kiasuwa and Marc Van den Bulcke



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European Guide on Quality Improvement in Comprehensive Cancer Control

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*The Editorial Team*



# List of abbreviations

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

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

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# Foreword

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

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

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

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

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

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

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

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

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# Introduction

Tit Albreht and Marc Van den Bulcke

## History

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

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

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

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

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

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

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

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

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

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

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

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

There were several tangible outputs of Slovenia's Presidency:

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

## Recent activities

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

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

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

EPAAC clearly evolved its activities around six different topics:

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

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

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

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

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

## Setting up of CanCon

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

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

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

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

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

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

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

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