

# EUROPEAN GUIDE ON QUALITY IMPROVEMENT IN COMPREHENSIVE CANCER CONTROL



## **Policy Paper on National Cancer Control Programmes (NCCPs)/**

### **Cancer Documents in Europe**

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## **1 Recommendations at a glance**

*Throughout this policy paper, the acronym NCCP will be used to refer to National Cancer Control Programmes and/or other cancer documents.*

**Recommendation 1:** Develop an NCCP if your country does not have one.

**Recommendation 2:** Use the European Guide for Quality National Cancer Control Programmes for the preparation of new NCCPs and for updating existing documents in order to improve quality.

**Recommendation 3:** Where NCCPs have been prepared but not yet implemented, NCCPs should be implemented as soon as possible.

**Recommendation 4:** Establish effective communication with the public regarding the implementation and/or evaluation of NCCPs.

**Recommendation 5:** Attempt to provide an institution with coordination functions that will have responsibility for cancer control at the national/regional level, if such an institution does not already exist.

**Recommendation 6:** Increase the involvement of patients and payers and reimbursement agencies in all stages of the preparation of NCCPs (strategic consulting, drafting, implementation, and evaluation) whenever possible.

**Recommendation 7:** Learn from strengths and weaknesses related to the process of drafting and implementation of NCCPs in other countries.

**Recommendation 8:** Ensure that your country's NCCP covers all of the key areas that should be included in a quality NCCP, as described in the European Guide for Quality National Cancer Control Programmes.

**Recommendation 9:** Ensure appropriate financial resources for the implementation of the NCCP.

**Recommendation 10:** Ensure availability of detailed instructions for the implementation of the NCCP.

**Recommendation 11:** Allocate specifically trained human resources for the implementation process, and outline how they will be involved within the NCCP.

**Recommendation 12:** Ensure a specific objective for every action taken in the NCCP.

**Recommendation 13:** Make specific alliances with relevant stakeholders, in order to ensure the implementation of the NCCP.

**Recommendation 14:** Make sure that indicators for evaluation are clearly defined in your NCCP.

**Recommendation 15:** Make sure to include process and structure evaluation in your evaluation strategy; do not rely on outcome evaluation alone.

## **2 Executive summary**

The present policy paper is a deliverable of the CanCon Joint Action Member State Platform Work Package. In this framework, an Expert Group on National Cancer Control Programmes (referred to in the text as “Expert Group”) was established with the task to carry out and analyse a survey regarding NCCPs in Europe in 2016 and to prepare a report and policy paper. The survey report identified the main shortcomings regarding NCCPs in Europe. Standards from the previously published *European Guide for Quality National Cancer Control Programmes* were used to identify these shortcomings (1). This policy paper and its recommendations are meant to serve as an aid for policymakers who wish to improve their cancer control policies.

## **3 Concepts used in this policy paper**

The World Health Organization (WHO) defined a National Cancer Control Programme (NCCP) as “a public health programme designed to reduce cancer incidence and mortality and improve quality of life of cancer patients, through the systematic and equitable implementation of evidence-based strategies for prevention, early detection, diagnosis, treatment and palliation, making the best use of available resources” (2).

Due to the fact that some European countries do not have a single document that addresses cancer at the national level, but instead have several documents addressing cancer at the regional level- which are not necessarily named programmes- the Expert Group agreed to use the term *cancer document/s* in addition to the official term *National Cancer Control Programme*. However, in this policy paper, the acronym NCCP will be used to refer to both National Cancer Control Programmes and other cancer documents.

## **4 Introduction**

National Cancer Control Programmes are key elements in cancer control, and their role in national cancer policies of European countries has grown significantly (2). In 2009 the European Commission called upon all Member States to adopt national cancer plans/strategies by 2013. Based on this

recommendation, many countries have decided to take steps and begun to develop their national/regional cancer documents (3).

The first survey on the situation regarding National Cancer Control Programmes in Europe was performed in 2011 under the Joint Action European Partnership for Action Against Cancer (**EPAAC JA 2011-2013**). At that time, a separate Working Group on Cancer Programmes was established and co-chaired by the European Commission and Slovenia. All European Member States, Iceland and Norway were invited to actively participate and contribute to its work. Answers to the abovementioned survey provided input for the comprehensive overview and assessment of the situation in the EU, Iceland and Norway regarding the availability of cancer programmes/documents in 2011.

In 2013 in the framework of the Joint Action European Guide on Quality Improvement in Comprehensive Cancer Control (**CanCon JA 2013-2017**), National Cancer Control Programmes were proposed as one of the most important areas for policy paper development. The process was the result of voting among the high-level representatives of Member States.

### **Methodology**

In the framework of the Member State Platform work package of the CanCon Joint Action, an Expert Group on National Cancer Control Programmes was established in 2013. One of the tasks of the Expert group was to carry out a survey to conduct an overview of the current situation (2016) in EU countries, Iceland, Norway, Turkey and Montenegro. A report was prepared based on the answers to the survey that serves as the baseline document for this policy paper. This policy paper is one of the main deliverables of the CanCon Member State Platform.

### **Why is a policy paper at the European level needed?**

Policy papers provide practical recommendations on which the European Commission and Member States can base concrete actions to improve the situation regarding NCCPs/cancer documents and consequent cancer control.

## **5 Aim**

This policy paper aims to shed light on the vital importance of the preparation, adoption, implementation and evaluation of quality National Cancer Control Programmes/cancer documents in

all European countries. Health systems can respond to population needs in the field of cancer only through adequate planning (4). The present policy paper provides recommendations that:

1. Enable policymakers to improve or develop their National Cancer Control Programmes/cancer documents,
2. Clearly show which tools to use in the improvement or development of National Cancer Control Programmes/cancer documents,
3. Make National Cancer Control Programmes/cancer documents more comparable and simplify the work of policy analysts who compare plans within European borders.

## **6 Recommendations with examples**

### **Recommendation 1: Develop an NCCP if your country does not have one.**

NCCPs are designed to reduce cancer incidence and mortality and improve quality of life of cancer patients, therefore they represent key elements of cancer management and control. In 2011 under the EPAAC JA, when the first survey on the situation regarding National Cancer Control Programmes in Europe was conducted, some countries reported having no NCCP. In 2016 the situation regarding the development of NCCPs improved, however, there are still countries without an NCCP.

#### **Example related to Recommendation 1: Development of an NCCP in Austria, Iceland and Luxembourg.**

In 2011 under the EPAAC JA when the previous survey on the situation regarding National Cancer Control Programmes in Europe was conducted, Austria, Iceland and Luxembourg reported that they did not have a national cancer document. In 2016 all three countries reported that they had prepared a national cancer document: Austria prepared a strategy, Luxembourg prepared a plan, and Iceland prepared a draft document.

### **Recommendation 2: Use the European Guide for Quality National Cancer Control Programmes for the preparation of new NCCPs and for updating existing documents in order to improve quality.**

NCCPs should be constantly improved and updated, and they should be considered to be living documents. Every country should- from time to time- evaluate the quality of their NCCP and try to improve and update the existing documents. The principle of multidisciplinary should serve as the cornerstone for the creation of NCCPs. The *European Guide for Quality National Cancer Control*

*Programmes* is a guide that shows the elements that should ideally be present in high-quality NCCPs. The Guide also shows those aspects of cancer management and control that should require special attention from policymakers (1).

**Example related to Recommendation 2: Use of the European Guide for Quality National Cancer Control Programmes in the preparation of the National Cancer Plan in Romania and in improvement of the quality of an already existing NCCP in Belgium.**

Romania presented the new National Cancer Plan in 2016. The key tool used in the preparation of the plan was the *European Guide for Quality National Cancer Control Programmes*. Romania reported being satisfied with the use of the Guide, which was very useful for their work, as was their participation in the EPAAC and CanCon Joint Actions. Belgium reported that they will use the Guide to modify and improve their plan in 2017.

**Recommendation 3: Where NCCPs have been prepared but not yet implemented, NCCPs should be implemented as soon as possible.**

The implementation of an NCCP is a demanding and conscientious process that requires the determination of certain institutions and bodies (for example Ministries of Health or other Ministries, Institutes of Public Health, coordinators, cancer societies, patient organisations and others) to carry it out.

**Example related to Recommendation 3: Implementation process of a new National Cancer Plan in Luxembourg.**

In Luxembourg the National Cancer Plan was adopted in July, 2014. Afterwards, the structures for its implementation were created (the National Cancer Platform and National Cancer Institute), responsibilities were determined, and an additional budget for the implementation of different measures was allocated.

**Recommendation 4: Establish effective communication with the public regarding the implementation/evaluation of NCCPs.**

Establishing effective communication with the public regarding the implementation/evaluation of NCCPs is of key importance. The most common ways of communicating with the public include websites, publications in different journals and scientific conferences, and other media such as print, radio or television. Several methods of communication with the public should be used to ensure communication is effective.

**Example related to Recommendation 4: Establishment of effective communication with the public regarding the implementation and/or evaluation of the NCCP in France.**

France reported the use of several methods of communication with the public regarding the implementation/evaluation of the NCCP. These included websites, public papers, journals, conferences, and an annual report to the President of France- which is available on the website.

**Recommendation 5: Attempt to provide an institution with coordination functions that will have responsibility for cancer control at the national/regional level, if such an institution does not already exist.**

It is advisable to attempt to establish an institution with coordination functions to be responsible for cancer control at the national or regional level. Such an institution could be an institute or cancer control centre.

**Example related to Recommendation 5: Establishment of the French National Cancer Institute (INCa) to be responsible for cancer control at the national level.**

In France the National Cancer Institute (INCa) was established in 2005, with the task to carry out cancer control at the national level. At that time, the first French cancer control plan was adopted.

**Recommendation 6: Increase the involvement of patients and payers and reimbursement agencies in all stages of the preparation of NCCPs (strategic consulting, drafting, implementation, and evaluation) whenever possible.**

The professional community, as well as Ministries of Health and Governments, are significantly involved in all stages of the preparation of NCCPs, including strategic consulting, drafting, implementation and evaluation in most European countries. The involvement of patients, patient organisations and payers or reimbursement agencies would be beneficial in order to collect better information on the economic and organisational aspects of NCCPs. The current involvement of patients and payers, however, is not adequate. Therefore, it is recommended that they be involved whenever possible.

**Example related to Recommendation 6: Inadequate involvement of patients in the implementation of the NCCP in Belgium, the Czech Republic and Sweden.**

Some countries including Belgium, the Czech Republic and Sweden identified the inadequate involvement of patients in the implementation of their NCCPs as a weakness.



**Recommendation 7: Learn from strengths and weaknesses related to the process of drafting and implementation of NCCPs in other countries.**

Almost all countries cope with certain issues in the process of drafting and implementation of their NCCPs. Specific issues that countries have encountered in the process of drafting and implementation of the NCCP, as well as the strengths and weaknesses, are described in the report, based on the analysis of data from the survey on NCCPs, carried out in 2015 (CanCon JA deliverable).

**Example related to Recommendation 7: The report based on the analysis of data from the survey-carried out in 2015 (CanCon JA) - on NCCPs will be available online at [www.cancercontrol.eu](http://www.cancercontrol.eu), so that policymakers can learn from the examples of other countries.**

**Recommendation 8: Ensure that your country's NCCP covers all of the key areas that should be included in a quality NCCP, as described in the European Guide for Quality National Cancer Control Programmes.**

A high quality NCCP should cover all of the most important areas: primary prevention, health promotion, cancer screening, early detection, diagnosis, treatment, psychosocial oncology care, survivorship, rehabilitation, palliative and end of life care, governance (management and planning of cancer services), financing, cancer resources (human resources, infrastructure, health technology, and cancer-specific expenditure), cancer data and information, research, access to innovative cancer treatments, patient orientation/patient empowerment and epidemiological trends (1).

**Example related to Recommendation 8: Based on the information collected on NCCPs, a large number of countries have already recognised the importance of including all of the key elements/areas in an NCCP; one-third of surveyed European countries include all key areas.** The elements are described in the *European Guide for Quality National Cancer Control Programmes* (1).

**Recommendation 9: Ensure appropriate financial resources for the implementation of the NCCP.**

Budgetary restrictions can influence decisions and priorities related to NCCPs, and thus it is not always possible to respect the key priorities of the NCCP. It is important to ensure a specific budget for the implementation of different measures planned in the NCCP and to make use of reallocation policies.

**Example related to Recommendation 9: Twelve countries (among them Belgium, Germany, Hungary, and Luxembourg) ensured appropriate financial resources for the implementation of different measures planned in the NCCP.**

**Recommendation 10: Ensure availability of detailed instructions for the implementation of the NCCP.**

Implementation of an NCCP is a complex and demanding process. Detailed instructions for the implementation are of great help to experts who are responsible for implementing NCCPs.

**Example related to Recommendation 10: Some European countries have ensured detailed instructions for the implementation of their NCCP.**

European countries are conscious of the complexity of the implementation process of an NCCP, and some of them have ensured the availability of detailed instructions for their implementation (for example Lithuania, Malta, Poland, Norway, and England).

**Recommendation 11: Allocate specifically trained human resources for the implementation process, and outline how they will be involved within the NCCP.**

It is recommended that specific human resources be allocated to the implementation process of the NCCP. Human resources that are specifically trained in the implementation of the NCCP should be planned to assure the success of the process.

**Example related to Recommendation 11: Some European countries have allocated specifically trained human resources to the implementation process.**

In some European countries (Belgium, Luxembourg, Sweden, and England) additional, specifically trained human resources were allocated to the implementation process. In France, for example, most of INCa human resources contributed to the implementation of the NCCP. Only a few European countries (for example the Czech Republic and France) have specified this in the NCCP.

**Recommendation 12: Ensure a specific objective for every action taken in the NCCP.**

It is important to closely link the actions taken in the NCCP to its objectives. It is recommended that a specific objective be ensured for every action taken in the NCCP.

**Example related to Recommendation 12: Some European countries ensure specific objectives for every action taken in the NCCP.**

Some European countries (for example Austria, Cyprus, Denmark, Finland, and Italy) ensured a specific objective for every action taken in the NCCP.

**Recommendation 13: Make specific alliances with relevant stakeholders, in order to ensure the implementation of the NCCP.**

In order to ensure the implementation of the NCCP, specific alliances with relevant stakeholders should be made. It is advisable to make alliances with academia, scientific societies, health care professionals, universities, patients, patient organisations, cancer societies, cancer registries, industry, local municipalities, cancer charities, or other related institutions.

**Example related to Recommendation 13: Alliances with stakeholders in order to ensure the implementation of the NCCP in Lithuania.**

In Lithuania professional and patient organisations, universities and local municipalities are included in the NCCP 2014–2025 implementation.

**Recommendation 14: Make sure that indicators for evaluation are clearly defined in your NCCP.**

Indicators are important in order to provide for the ongoing assessment of the implementation process and the objective evaluation of the targets set out by the NCCP. It is recommended that indicators be clearly defined in the NCCP.

**Example related to Recommendation 14: Indicators for evaluation are clearly defined in NCCPs in some European countries.**

In Austria, Slovenia and Estonia indicators for evaluation are clearly defined in their NCCPs.

**Recommendation 15: Make sure to include process and structure evaluation in your evaluation strategy; do not rely on outcome evaluation alone.**

In order to improve the monitoring and evaluation of NCCPs, it is recommended that process and structure evaluation be carried out in addition to outcome evaluation, which is the most frequently used method of evaluation in Europe. The added value of using all three different types of evaluation is a more in-depth understanding of the process and structures that lead to the desired outcome.

**Example related to Recommendation 15: Some European countries evaluate their NCCPs by outcome, by process and by structure.**

To assure accurate results, Belgium, Cyprus, Denmark, Germany, Italy, Lithuania, Luxembourg, Spain, Sweden, Turkey and Wales evaluate their NCCPs using all three methods of evaluation: by outcome, by process and by structure.

## **7 Authorship**

This policy paper represents the joint work of members of the Expert Group on National Cancer Control Programmes in the framework of the CanCon Joint Action Member State Platform. Members of the Expert Group on National Cancer Control Programmes are (in alphabetical order): Tit Albreht, National Institute of Public Health, Slovenia; Karen Budewig, Ministry of Health, Germany; Patricia Fitzpatrick, University College Dublin, Ireland; Marjetka Jelenc, National Institute of Public Health, Slovenia; Aneta Modrzynska, Ministry of Health, Poland; Francois Schellevis, NIVEL (Netherlands Institute for Health Services Research), The Netherlands; Branko Zakotnik, Institute of Oncology, Slovenia and Elisabete Weiderpass, Karolinska Institute, Sweden.

## **8 References**

1 Albreht T, Martin-Moreno JM, Jelenc M, Gorgojo L, Harris M. European Guide for Quality National Cancer Control Programmes. National Institute of Public Health. Ljubljana, 2015.

2 Haward R. Organizing a comprehensive framework for cancer control. In: Coleman MP, Alexe DM, Albreht T, McKee M. Responding to the challenge of cancer in Europe. Institute of Public Health of Slovenia. Ljubljana, 2008.

3 World Health Organization. National cancer control programmes: policies and managerial guidelines. Geneva: WHO; 2002.

4 Albreht T, Jelenc M, Gorgojo L. From »on paper« to »into action«: development of National Cancer Control Programmes in the EU. In: Martin-Moreno JM, Albreht T, Radoš Krnel S. Boosting Innovation and Cooperation in European Cancer Control. National Institute of Public Health. Ljubljana, 2013.