Developments in National Cancer Control Programmes in Europe – Results From the Analysis of a Pan-European Survey

Marjetka Jelenc, MD, PhD¹, Elisabete Weiderpass, MD, PhD², Patricia Fitzpatrick, MD, PhD³, and Tit Albreht, MD, PhD¹,4

Abstract

Introduction: National Cancer Control Programmes (NCCPs) provide a country’s policy framework for the development of cancer control, focusing on the reduction of cancer morbidity and mortality and improving quality of life of cancer patients.

Objective: Exploring and analysing to which extent some of the key elements of the European Guide for Quality National Cancer Control Programmes (Guide) are implemented in NCCPs in the EU.

Methods: Survey carried out through 30 countries, EU members, Iceland, Montenegro, Norway and Turkey, focusing on stakeholders’ participation, inclusion of all the envisaged chapters from the Guide as well as implementation and dissemination.

Results: The results of the policy survey on European NCCPs carried out within Cancer Control Joint Action (CANCON JA) are presented. The response was 30 out of 35 countries. In total, 28 out of 30 countries, which completed the survey, had an NCCP or another cancer document. Cancer documents were mostly single documents, managed and supervised by the respective Ministries of Health and communicated to the public via websites and press. Nine documents were defined as programmes, eight as plans and six as strategies; in five countries, terminology was mixed. Regarding the content, recommended by the Guide from 2015, comprising ten chapter areas in three parts. Only 10 countries included in their NCCPs all elements suggested in the Guide.

Conclusion: Based on our results, we can see that a more comprehensive approach in the process of NCCPs is needed. Policy should focus on the development of instruments for efficient cancer management, which would encompass the entire trajectory of the cancer care from diagnosis to survivorship and supportive care.

Keywords
cancer, oncology, European Union, cancer policy, National Cancer Control Programmes, management

Introduction

Management of cancer control is inherently complex, requiring multifaceted and simultaneous interventions. These can be achieved through adequate planning in response to population needs by preventing, detecting and treating this disease as quickly and effectively as possible. National Cancer Control Programmes (NCCPs) are defined by the World Health Organization (WHO) as ‘public health programmes designed to reduce cancer incidence and mortality.

¹National Institute of Public Health, Ljubljana, Slovenia
²World Health Organization, International Agency for Research on Cancer, Lyon, France
³Physiotherapy and Sports Science, School of Public Health, University College Dublin, Dublin, Ireland
⁴Department of Public Health, Faculty of Medicine, University of Ljubljana, Ljubljana, Slovenia

Corresponding Author:
Tit Albreht, National Institute of Public Health, Ljubljana, Slovenia, Trubarjeva 2, Ljubljana 1000, Slovenia.
Email: tit.albreht@nijz.si

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and improve quality of life of cancer patients, through the systematic and equitable implementation of evidence-based strategies for the prevention, early detection, diagnosis, treatment and palliation, making the best use of available resources.\(^1\),\(^2\) NCCPs are therefore useful tools in supporting efforts of health systems in responding to the challenges posed by the cancer epidemic and its complexity.\(^3\)

Over the past 25 years, we have seen the gradual uptake of cancer programmes in many countries all over the globe. European Union (EU) has produced some of the more innovative and pioneering initiatives in the field of NCCPs. France, England and Norway paved the way for the EU-wide discussion on the need to establish national or regional cancer programmes, plans or strategies in all EU Member States (MSs).\(^4\),\(^5\)\(^6\) This led to gradual developments of NCCPs across the EU.\(^7\)

The European Parliament and Council urged the European Commission (EC) to take vigorous action in supporting MSs in the fight against cancer.\(^8\),\(^9\) In 2009, EU recommended to its MSs to develop NCCPs or Strategies by 2013.\(^10\),\(^11\) The EC instrumented its policy preparation through projects called Joint Actions (JAs): EPAAC JA, 2011–2013 (www.epaac.eu) and CANCON JA, 2014–2017 (www.cancercontrol.eu).\(^12\),\(^13\) The current JA, Innovative Partnership for Action Against Cancer (iPAAC JA), started in 2018 and the results will be available in late 2021.\(^14\)

The area of NCCPs has been an important working topic in all three JAs where the implementation of NCCPs as well as their contents was explored. The Expert Group on National Cancer Control Programmes in the frame of CANCON JA agreed to additionally use the term cancer document/s beside the official term NCCP.

The aim of this study is to present the main findings from the policy survey on European NCCPs carried out within CANCON JA. This was the second survey of its kind, and the first survey took place in 2011 and was a part of the EPAAC JA.\(^15\)

## Material and Methods

Within the CANCON JA, a special Expert Group was established to work on the exploration of NCCPs. Members from different participating countries were entrusted with the preparation of a survey on NCCPs. It was intended to provide an overview of the situation regarding the NCCPs in the EU, all UK countries, Iceland, Norway, Turkey and Montenegro. Based on the answers to the survey, the analysis and the report\(^16\) were prepared. The report was the main input for the position paper regarding the situation on NCCPs in the EU.\(^17\)

The survey had four sections, which are presented in Box 1. It was sent to 35 countries, including all EU MSs, UK countries, Iceland, Montenegro, Norway and Turkey.

| Box 1. Organisation of questions in the survey. |
| --- |
| **Section 1 – Situation:** existence, type and number of cancer documents as well as availability and the communication with the public, responsibility for the adoption/publishing and implementation of NCCP, integration of cancer control into other policies/legislation/strategies, presence of institutions to carry out cancer control at national/regional level and to dedication to coordination of actions related to the NCCP. |
| **Section 2 – Process:** drafting of the NCCPs, including the involvement of stakeholders in the preparation of the idea, consulting, drafting, implementation, evaluation or drafting of a new NCCP, specific actions undertaken in order to create the NCCP, main strengths and weaknesses that have been identified in drafting the contents of the NCCP, dealing with challenges or problems at the drafting stage of the NCCP as well as the timeframe for development of the NCCP, general elements of NCCP and to the influence of budgetary restrictions. |
| **Section 3 – Implementation:** implementation of the NCCPs, including budgetary considerations, establishment of the necessary structures for the implementation, availability of detailed instructions for the implementation, institutions responsible for the implementation and its functioning, human resources allocated to the implementation, strengths and weaknesses identified in implementing the NCCP, duration of validity of the NCCP, specific objectives for every action taken in the NCCP and specific alliances made with other relevant stakeholders in order to ensure the implementation of the NCCP. |
| **Section 4 – Evaluation:** evaluation of the NCCPs, including the use of indicators or criteria for the evaluation process, list of indicators and their inclusion in the NCCPs. |

Members of the Expert Group compiled the list of contact points responsible for NCCPs in the participating countries, which received the survey at the end of 2015 and were asked to complete it within seven weeks. Completed surveys were analysed and the answers were structured across the sections and in the overarching topical findings.

## Results

Thirty out of 35 countries (response rate 85.7%) responded to the survey, of which 28 reported having an NCCP or another cancer document. Only two of the countries, which completed the survey, did not have an NCCP. Of the five non-respondents, two countries did not have an NCCP.

The results below are based on the 28 responding countries. The numbers in tables and figures below represent the number of countries. Cancer documents were predominantly single documents, managed and supervised by the respective Ministries of Health and communicated to the public via websites and through press. Nine documents were defined as programmes, eight as plans and six as strategies; five countries used mixed terminology (eg programme and policy; plan and strategy; strategy and regional plans).
In all except two countries NCCPs were available on the web. Iceland and Romania reported that their NCCPs were not available on the web because both documents were draft documents and not ready for publication. NCCPs were available through different communication channels, which are presented in Table 1.

In 23 countries, the communication with the public regarding the implementation/evaluation of the NCCP was established. In 27 countries, it was through websites, publications in different papers and in press in general, as well as press conferences. The Ministry of Health (MoH) is responsible for the implementation of the NCCP in 11 countries, while in most countries there are two or more institutions responsible. In all, but two countries cancer control is linked up with other policies, legislation or strategies. Countries with an NCCP decided to link cancer control with existing cancer-specific and/or cancer non-specific segments of health care and they have a national (or regional) authority dedicated to coordination of actions related to the NCCP, in 11 countries it is the MoH. Roles of different stakeholders in the different stages of the process are presented in Table 2, quoting the number of countries, which reported the involvement of the specific stakeholder in the processes listed.

**Table 1.** Communication Channels for the Availability of NCCPs Used by Countries.

| Types of communication channels                                           | Number of countries |
|---------------------------------------------------------------------------|---------------------|
| Websites of the Ministries of Health                                      | 17                  |
| Governmental websites                                                     | 10                  |
| Either on National Cancer Center website or on the websites of non-governmental organizations (NGOs), respectively | 6                   |
| Website of the national institutes of public health                       | 3                   |
| In media, as press releases, lay press or in social media                 | 2                   |
| Other ways of publishing as special web pages                            | 2                   |

Respondents described their self-perceived strengths in the drafting of their NCCPs. Figure 1 represents the methods used in the development of the NCCP.

Seventeen countries cited the involvement of experts and relevant stakeholders during programme formulation among the main strengths. Examples include the following: positive contributions by non-governmental organizations (NGOs) and cancer patient organisations, the involvement in the European projects EPAAC JA and CANCON JA as well as focussing on priorities and cooperative thinking, promotion of networking and evolution of common responsibility.

Drafting was mostly done through discussions, consensus meetings and negotiations. Other interesting methodologies reported were as follows: involvement of international advisors, head of the state involvement or priority settings. NCCPs development time ranged from less than one to five or more years. Overall, the average period was between 2 and 3 years. Three countries reported that their process of development was ongoing.

Ten countries reported that their NCCPs cover all the elements recommended in the Guide. The number of countries which included specific areas in their NCCPs is presented in Table 3. Areas not specifically mentioned in the Guide are shown in italic.

More than half of the respondents reported that budgetary restrictions did not impact decisions and priorities in their NCCPs. Thirteen countries established a specific earmarked budget for the implementation of the NCCP. But, the other half of the countries answered that there was no specific budget allocated to the implementation.

Relationship between financing and implementation of NCCPs on the basis of responses from 26 countries (2 countries did not provide a specific answer to this question) is presented in Table 4.

Actors involved in the implementation of NCCPs in respondents are presented in Figure 2.

![Figure 1. Organisation of the development of the NCCP, adapted from Ref. 16.](image-url)
There is usually a special body for the implementation of the NCCP, and countries reported from one to twenty-six additional specifically trained human resources allocated to the implementation process. Except in Turkey, which reported that more than 1400 professionals were involved, human resources allocated to the implementation process are mostly not detailed. The validity of the NCCP is usually from 3 to 5 years, in three countries 10 years or more. In some cases, NCCPs are open-ended with continuous updating.

Evaluation of the implementation was envisaged in all countries, as it was also in 2011 when the first survey was performed. Evaluation typologies and the number of countries are presented in Table 5. Fourteen countries would have midterm and final evaluation, in five countries only final evaluation was planned. Fourteen countries reported that the same bodies are responsible for the evaluation and implementation of their NCCPs. Twenty-four countries reported that indicators/criteria are/will be used in the process of evaluation of their NCCPs, and 16 have defined them in the document. In 2011, only 22 countries reported that indicators/criteria are/will be used in the process of evaluation of their NCCPs, which indicates the improvement of the situation in the results presented here.

**Discussion and Conclusions**

Through the application of science to public health practice, NCCPs provide the framework for the development of policies on cancer control, with the ultimate goal of reducing cancer morbidity and mortality and improving quality of life.\(^7,19\) When developed and implemented effectively, they improve cancer outcomes at the population level.\(^7\)

A lot of work has been done in the field of NCCPs in the period of more than 10 years since Atun et al\(^2\) published the first major research concerning NCCPs in Europe. The analysis was based on 19 publicly available NCCPs; 12 of the countries studied had yet to formulate or renew their NCCPs. Most of the programmes had significant gaps, for example, in relation to governance, macro-organisation of the health system for cancer care, financing and resource allocation for NCCPs as well as targets and timelines for achieving them. With this scenario in mind, in 2009, under the EPAAC JA, the EC called upon the MSs to set up national cancer plans or strategies by the end of 2013. Under the EPAAC and the CANCON JAs, two surveys have been performed with the purpose of informing EU policymakers about the extent to which this goal has been achieved.\(^14,16\) At the time of the analysis of Atun,\(^2\) there were no clear instructions regarding the content of the NCCPs; this important gap was filled with the results of the EPAAC JA project when the Guide was created.\(^18\) Since then, European countries have clear instructions for producing quality NCCPs. However, there are

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**Table 3.** The Number of Countries Which Included the Listed Key Elements in their NCCPs.

| Elements of NCCP                        | Number of countries |
|----------------------------------------|---------------------|
| Early detection                        | 28                  |
| Cancer screening                       | 27                  |
| Cancer data and information            | 27                  |
| Diagnosis                              | 26                  |
| Epidemiological trends                  | 26                  |
| Health promotion                       | 26                  |
| Treatment                              | 26                  |
| Primary prevention                     | 25                  |
| Palliative and end-of-life care        | 25                  |
| Patient orientation/patient empowerment| 24                  |
| Psychosocial oncology care             | 23                  |
| Survivorship                           | 23                  |
| Governance                             | 23                  |
| Research                               | 23                  |
| Access to innovative cancer treatment  | 19                  |
| Cancer resources                       | 18                  |
| Financing                              | 15                  |

**Table 4.** Relationship Between Financing and Implementation.

| Number of countries | Adequacy of financing | Implementation |
|---------------------|-----------------------|----------------|
| 13 Additional financial resources         | Successful           |
| 8 Lack of financial resources                  | Endangered           |
| 5 Lack of financial resources                  | Successful           |

**Figure 2.** Actors in implementation of the NCCPs.

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more and more improvements in cancer management in individual countries, including specific terminology (eg., contact nurses and individually written care plans in Sweden) suggesting a need for the improvement of the Guide, which is a living document.

In the last decade, a substantial number of MSs in the EU have formulated and/or updated their NCCPs, plans or strategies. Twenty-eight out of thirty countries, which completed the survey, reported to have an NCCP or other cancer document in 2016. In fact, the answers to the extensive survey on NCCPs in the frame of CANCON JA provided a clear overview of the situation regarding these important documents in the EU in 2016. Despite evidence of a historically large and growing cancer burden, cancer services have not generally been prioritised in low- and lower-middle-income countries by national governments or external funders. Our analysis shows that, generally, cancer documents lacked dedicated subchapters and allocation of financing, of additional resources and on access to innovative medicines. In eight countries, the implementation of the NCCP was endangered due to the lack of financial resources.

Involvement of stakeholders in the processes of ideas, preparation, drafting, implementation and evaluation of the NCCPs was mostly on the side of the policymakers and the professional community. Participation of the patient community and of the payers was much less pronounced. Patients were involved most commonly in the drafting but much less so in the implementation and evaluation stages. Professionals’ involvement made a crucial contribution in all countries that completed the survey. The majority of countries (21 countries) considered the involvement of patients and regional/local authorities an important strength as well. In only ten countries all elements of the Guide were included in their NCCPs. Generally, cancer documents lacked dedicated subchapters and allocation of financing, of additional resources and on access to innovative medicines. Lack of financial resources or/human resources and/or equipment was identified as main weakness in nine countries, while some countries reported lack of patient involvement as main weakness. There is a variety of terms to describe national cancer planning documents, including plan, programme and strategy. Additionally, in the case of federal countries, there are several documents in place, the national plan as well as regional ones. Among the most important findings were the main deficient areas in NCCPs which are economics of cancer care and control as well planning of resources for cancer care. Findings support the need to monitor the ongoing and quickly developing activities on NCCPs, which have taken ground in the second decade of this century. Cross-country learning and exchange of experiences can bring good practices to wider use and implementation.

Disclaimer

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ORCID iD

Tat Albreht https://orcid.org/0000-0002-1812-4381

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