

Final Publishable Executive Summary

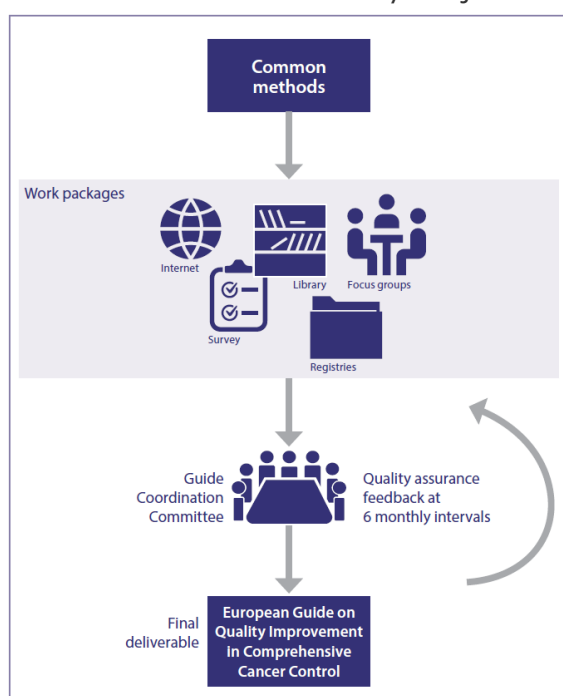
Cancer is currently the second most common cause of death in the EU and continues to represent a tremendous burden on EU societies and health systems. The CANCON Joint Action on comprehensive cancer control is the second Joint Action on cancer to be co-funded by the EU and builds upon the work of the European Partnership for Action Against Cancer Joint Action and other EU initiatives.

The main objective of CANCON was to contribute to improvements in overall cancer control throughout the EU through the production of the European Guide on Quality Improvement in Comprehensive Cancer Control. The Guide was to cover the areas of quality-based cancer screening programmes, better integration of cancer care, community-based cancer care approaches and survivorship, including palliative care.

More specifically, the aim for work on screening was to create guiding principles for better governance, organisation (planning, implementation and management) and evaluation of population-based cancer screening programmes. In the field of cancer care, the goal was to provide an articulate plan that would enable access to comprehensive cancer services and to optimal cancer care for the entire people of a particular territory through the synergy of all relevant institutions that have complementary expertise, coming together in a Comprehensive Cancer Care Network (CCCN). Another goal was to improve community-level cancer care by exploring patient pathways for the after-care of cancer survivors at primary level. The final objective of the Guide was to develop a European organisational framework that would include a detailed list of recommendations to be tackled to address survivorship, rehabilitation and palliative care.

The other key objective of CANCON was the establishment of a Member State Platform, whereby Member States could share knowledge and experiences and discuss the most relevant topics in the field of cancer control. Based on the discussion and work of the core writing teams, Policy Papers were to be written for each of the selected topics.

The majority of the work within CANCON was therefore focused on the two main deliverables, the Guide and the Policy Papers. Work on the Guide was coordinated by the Guide Coordination Committee, which served as the oversight group for Guide production. The Guide includes four key subject areas, which are reflected in the organisation of the CANCON Work Packages and Guide chapters.



The key areas covered in the Guide are:

- Cancer screening, with policy recommendations on governance, organisation and evaluation
- Integrated cancer control, with policy recommendations on establishment of comprehensive cancer care networks (CCCN)
- Cancer after-care at the community level, with policy recommendations for quality improvement
- Survivorship and rehabilitation, with policy recommendations for quality improvement

Figure 1: Quality assurance process in development of the Guide

The working groups for each of the four key areas used a variety of methods to underpin their policy recommendations. These ranged from literature reviews, surveys and expert opinions, semi-structured interviews, grading/appraisal and field/pilot studies. Such a multi-faceted approach led all four working groups to produce recommendations based on the findings of their working groups and corresponding chapters of the Guide.

Within the framework of the Member State Platform, Member States first met to select topics which would eventually become Policy Papers. Based on strategic relevance and scientific feasibility, five topics were selected:

- Public Health Genomics in Cancer
- National Cancer Control Programmes/Cancer Documents in Europe
- Enhancing the Value of Cancer Care Through a More Appropriate Use of Healthcare Interventions
- Tackling Social Inequalities in Cancer Prevention and Control for the European Population
- Impact Evaluation System to Assess Prevention Outcomes

Core Writing Groups (CWG) were formed for each topic. Each CWG had a coordinator and was comprised of interested Member State representatives, partners, experts and collaborating partners. Experts were chosen through an open call, which contributed to the diversity of collaborators working on these tasks. In drafting the papers, CWGs used a variety of methods, utilising systematic reviews, national reports and qualitative data on national policies, as well as surveys filled in by Member States, with a view to providing practical and evidence-based recommendations for Member State use. Several drafts of each Policy Paper and discussion in Member State Platform meetings led to the completion and finalisation of all five papers towards the end of the JA.

Throughout the work on the two parallel objectives of the Guide and Member State Platform, the feedback and invaluable work of Collaborating Partners and other stakeholders fed into and informed the working groups for the Guide and Policy Papers through annual Stakeholder Forum meetings.

The main target group for dissemination of CANCON deliverables were policy- and decision-makers at EU and national levels. Annual Policy Conferences were held to target this group specifically and served as an invaluable forum in which to present CANCON work directly to policy-makers at EU and national levels and informed the work of all working groups in making the final outputs concise, yet comprehensive and policy-friendly. National level policy conferences were additionally utilised by several partners to disseminate the outputs of CANCON in local contexts and languages.

The final versions of the Guide and Policy Papers were timed to be launched in printed form at the closing conference of CANCON in Malta from 14-15 February 2017. Over 220 attendees from throughout Europe attended the final CANCON event to hear about the CANCON recommendations and find out more about the main deliverables, as well as discuss implementation and sustainability.

Throughout the Joint Action, regular evaluation took place through interim evaluation reports. Surveys and semi-structured interviews were the most commonly utilised tools for evaluation. Various target groups were defined based on the timeframe of evaluation, with Associated and Collaborating Partners, as well as Member State representatives all targeted with specific evaluation surveys on key events or the status of the JA and achievement of objectives. Specific attention was paid to evaluation of added value of the JA and its outputs for Member States.

The major results of the CANCON Joint Action are the policy recommendations set out in the European Guide on Quality Improvement in Comprehensive Cancer Control and the five Policy Papers arising from the Member State Platform.

The major result of the work on Integrated Cancer Control was that a full consensus was reached with respect to the definition, the structure and the ideal operational method of a CCCN, an effective way to provide for the needs of a cancer patient population within a precise geographic region. The recommendations have been tested through the real-life establishment and implementation of a pilot CCCN in the Czech Republic. The pilot CCCN was initiated in 2015 and established in an area covering a population of 1.6 million inhabitants, incorporating one comprehensive cancer centre, three specialised cancer centres and four general hospitals. The key principles of forming a CCCN, as defined by the CANCON working group, have been taken into account.

For community-level cancer care, the key messages are that cancer should be managed as a continuous process where patients pass (transit) different phases and stages. There should be a dynamic coordination and flow of information between specialised oncology care and community care. Education and training should be provided for primary care providers so that they can cope with increasing numbers of cancer patients in after-care. A pilot study on after-care for cancer survivors at primary level was taken up in Slovenia. The Skinmama digital campaign, available at www.skinmama.eu, aimed at increasing awareness of skin cancer prevention messages among youth populations in the EU and utilised community approaches to promote awareness and early detection. The process of after-care is also insufficiently covered by adequate guidelines and should instead aim for clear patient pathways, including a clear allocation of responsibilities of the different providers of different services pertinent for this part of the care process.

Key findings from the work on survivorship and rehabilitation include the fact that cancer survivors' follow-up, late effect management and tertiary prevention needs to be anticipatory, personalised and implemented by means of care pathways, with active participation of survivors and relatives. The improvement of early detection of patient's needs and the access to rehabilitation, psychosocial and palliative care services is required. An integrated and multi-professional care approach with a coordination of community care providers and services are needed to implement a Survivorship Care Plan.

National structures for governance of screening have been identified as important requirements for evidence-based decision-making and for establishing adequate legal, financial and organisational frameworks for effective cancer screening programmes with integrated quality assurance. Transparent, structured and publicly documented decision making is recommended, with informed political commitment and broad stakeholder involvement in order to build strong professional support for the aims and means of the screening programme.

A variety of policy recommendations have also been made in all five of the Policy Papers aimed for use by EU Member States. The Guide and Policy Papers, as well as a summary of all the recommendations, can be accessed at <http://www.cancercontrol.eu/guide-landing-page>.

All of CANCON's activities have been oriented to reducing the burden of cancer in EU Member States, directly benefitting the general public, cancer patients and survivors. The policy recommendations set forth in the Guide and Policy Papers, if utilised, implemented or adapted for national and local use, have the potential to significantly improve the quality of cancer control in EU Member States. This could reduce inequalities amongst cancer patients and differences in outcomes amongst EU Member States. Additionally, Member States and healthcare professionals benefit from the creation of a vast network of cancer control stakeholders in Europe, which is a significant tool for further work on implementation and national adaptation of the CANCON recommendations.