Chapter 2

European Guide on Quality Improvement in Comprehensive Cancer Control

Context, summary recommendations and appraisal

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Introduction

Cancer control is a complex and challenging topic. Many people are affected directly or indirectly by the health effects of cancer and many people directly or indirectly participate in cancer control. While there are many individual interactions between patients and a wide range of formal and informal care providers through the delivery of care, comprehensive cancer control further encapsulates all of the additional resources and activities that contribute to the governance, financing and management of cancer services and systems.

Over time, incidence and prevalence have been increasing for most cancers through a number of factors, including ageing populations and increasingly more effective treatment interventions. Alongside this, unacceptable cancer inequities exist both between and within European countries. The evolving shift in several types of tumour to cancer as a chronic disease requires health systems to examine better ways to organize and structure their investments and efforts to provide effective, comprehensive and equitable cancer control that meets the various needs of cancer patients along the extended trajectory of their experience with the disease. The European experience suggests that while most key cancer control challenges and issues are universally faced, approaches to address them successfully have both common and country-specific elements and consequently guidance requires a contextual lens. CanCon provides an important opportunity to examine these varied approaches to improve cancer control amid the mix of prevailing health system contexts and experiences with the intention of supporting the operationalization and application of evidence-informed guidance to specific settings.

This chapter will first situate the Guide within the context of other European initiatives by documenting a few examples that have been promoted or supported by different stakeholders in order to improve cancer control; it will then go on to discuss the growing need for system-level guidance and the rationale for the Guide's four areas of focus. An overview of the Guide's recommendations are given and then appraised before concluding with an assessment of future opportunities for comprehensive cancer control.

European initiatives to improve cancer control

One of the most relevant changes in cancer control strategy has been the consolidation of the European-level perspective of many initiatives since the Europe Against Cancer programme initiated in 1985 by the European Council and a Committee of Cancer Experts. From an initial focus on information systems, primary prevention and screening, cancer control programmes and activities have extended their coverage to include cancer care, particularly regarding psycho-oncology, quality-of-life issues and palliative care, as well as the need to have population-based data from cancer registries in order to assess the quality of cancer care outcomes. Although not all countries have yet managed to institute all programme elements, the publication of successive EUROCARE results from the mid-1990s until EUROCARE V, which compare the relative survival by country and tumour site, has been a landmark to this end, associating the possible role of cancer care quality, organization and delivery with the remarkable differences observed among European countries *(1,2)*. Thanks to the standardized collection of data, the extent to which these variations could be attributed to methodological differences in data collection has been minimized.

The organization of cancer care could be viewed as a laboratory of many organizational changes in health care at micro- (clinical management), meso- (health care organization) and macro- (health system) levels. A clinical management example is the conceptualization and extensive application of multidisciplinary teams and the evaluation of their impact on health outcomes *(3,4)*. From a health system level, an example could be the progressive acknowledgement and wide adoption of the need to assess the delivery of cancer care across its continuum through the national cancer plan perspective. Since the landmark example given by the Calman-Hine Report, with a proposal of a reorganization of the provision of care in England and Wales in order to improve the outcomes for patients among different measures, cancer control programmes have adopted progressively a broader perspective along the continuum in different EU countries *(5)*. In this respect, the Institute of Medicine published a report in 1999 (Ensuring quality cancer care) that considered the existing gap between ideal quality of cancer care that could be provided to patients and the real-life care received; the proposed recommendations included improved access to hospitals with extensive experience in complex procedures, development of evidence-based guidelines, improved end-of-life care and monitoring of the quality of cancer care, among others *(6)*. Although progress has been made in these recommendations since the publication of the report *(7)*, it is notable that the same institution felt it necessary to re-assess the situation 15 years later and then reviewed the recommendations with more emphasis on survivorship, accessible and affordable care, translation of evidence into clinical practice and the development of the capacity of a learning health care system in the field of oncology (8). In summary, the core of many activities carried out by governments, scientific societies and patient organizations is how to deal with the challenges posed by the evolution of the changing needs of patients, the improvements required in access and quality of cancer care and the organizational requirements to cope with innovations in cancer screening and care. This growing involvement of stakeholders in cancer control activities has also

taken place at the European level, in close interaction with EU Commission initiatives and national cancer control plans. As a framework to the recommendations of the CanCon project, a brief review of the initiatives set up at EU level will be presented to outline the state of the art situation and its alignment with CanCon efforts.

Consensus on the evidence for primary prevention and screening: the European Code Against Cancer

The European Code Against Cancer has reached its third edition, using a consistent approach throughout, combining evidence-based review of the scientific literature about primary prevention and screening with the publication of a list of specific and clear recommendations for the general population about what to do in order to prevent cancer. The reviews of each recommendation have been published in Cancer Epidemiology *(9)* jointly with the list of recommendations. It is worth highlighting the effort to build a consensus about aspects of prevention and screening, such as dietary recommendations or breast screening, which have been surrounded by controversies from different perspectives since the first version of the European Code. There is wide consensus about the relevance and usefulness of this approach as the scientific background for creating messages aimed at achieving effective cancer prevention.

Reference networks for cancer care at EU level: the case for rare cancers

Rare cancers have generated strong interest at the EU level, as shown by different EU-funded projects. In a combined multistakeholder initiative, the European Society for Medical Oncology led Rare Cancer Europe, which includes support for actions at the EU level to build reference centres, disseminate high-quality clinical guidelines and address obstacles for patients to access appropriate therapies *(10)*. This is the approach adopted in the EU policy of developing European reference networks, such as the Directive on Cross Border Health Care, and in course of implementation with applications for rare cancers for both adults and children. This offers a framework for organizing access to knowledge and care, when required, for clinical services with high-quality experience in dealing with the diagnosis and treatment of this group of rare cancers. The new Joint Action on Rare Cancers, which begins its three-year period of work at the end of 2016, involves country-specific cancer plans, cancer registries, scientific societies and patient organizations and will deliberate on the opportunities and challenges for these groups of cancer. This collaboration perfectly illustrates the potential advantages of a European-level perspective. It offers an opportunity to explore the issues of coordination of care among different partners, levels and specialties that is at the core of any improvement in the continuum of care. It is also worth noting the importance of patient associations in this field, as well as in other areas of cancer control, which have been instrumental in the development of several European projects that have paved the way for initiatives such as the European reference networks.

Initiatives by scientific societies: building blocks for cancer control policy at the EU level

Policy and organizational aspects of cancer care have been highlighted by the innovative character of cancer care fuelled by research progress, the need for coordination of different specialists in a multidisciplinary approach to the diagnosis and treatment of cancer patients as well as by the challenges posed by the organization of care involving different levels of care and transitions among them *(11)*. All these factors should be combined with the increasing costs of cancer care in order to assess the relevance of involving all stakeholders in order to agree on the way ahead. Many actors take part with different degrees of influence, but there is no question about the essential role that scientific societies should play in the development of cancer control policy, in parallel with the essential contribution of patient associations. Indeed, scientific societies have shown their willingness through different initiatives, which can be grouped under the global framework of oncology policy. Some examples will be briefly summarized in order to highlight their relevance for European cancer control.

EURECCA is an initiative of the European Society for Surgical Oncology that is aimed at assessing the outcomes of cancer surgical procedures for specific tumour sites, such as breast, oesophageal, pancreas and rectal cancers and liver metastasis *(12)*. It involves the collection of all the cancer procedures with a detailed list of key clinical variables of all the patients with a specific tumour site, using data from population-based cancer registries when possible, although other comprehensive databases have been used (e.g. discharge information from administrative data sources for pancreatic cancer) *(13)*. This initiative from a scientific society could provide essential clinical and epidemiological data variables combined to compare the performance of different health care systems, either at national or regional level; this will allow a rational discussion about the quality of care provided. The diversity of countries involved so far makes feasible this comparison and, in combination with the professional involvement, makes a remarkable and relevant initiative at EU level.

One of the major challenges is the increasing budget devoted to cancer care because of the cost of all innovative therapies (including but not exclusively drugs) introduced or under evaluation. The relevance of assessing the magnitude of the benefit of the new drugs approved in a rational way is an activity undertaken by the European Society for Medical Oncology. Its Magnitude of Clinical Benefit Scale was developed to grade the effects of new drugs for each tumour and indication, using data from clinical trials or meta-analysis of trials, with different criteria for palliative and curative indications *(14)*. This scale could provide a meaningful ranking of the magnitude of the clinical benefit that could be expected from a new therapy, which is a key variable in order to assess the value of the drug and opens the possibility for more rational policy. The European Society for Medical Oncology is also convening a group to assess access to expensive, innovative cancer medicines in order to explore different policy options and suggest actions either at international or national levels. These activities could be seen as parallel to efforts of the American Society of Clinical Oncology, such as Choosing Wisely (15), or its statement of the value of cancer care (16), all of which aimed at evaluating the options to support a sustainable cancer system and one that allows innovation to be accessible to all patients that may require it.

With a different perspective, the European Society for Radiotherapy and Oncology has set up a group to assess the status of equipment, workforce and guidelines for planning radiotherapy in all European countries, as well as to assess the need for radiotherapy treatment using an evidence-based model of the indication for therapy *(17–20)*. A further development of the Health Economics

in Radiation Oncology Group will be building a model for assessing the cost of radiotherapy and the analysis of reimbursement by country. The perspective used is a combination of the collection of data at the national level with common methodology, allowing for cross-national comparisons with adjustment for the population-based cancer incidence, which provides a set of data useful for national cancer plans and for assessing the gap between optimal and actual use of radiotherapy *(19)*.

The last example is the ongoing programme launched by the European Cancer Organisation, the umbrella organization of cancer societies in Europe, on the essential requirements for quality cancer care, which will be focused by tumour site, with the first being colorectal and bone and soft sarcomas. This initiative will combine the evidence base with expert input to evaluate the resources required to offer quality care, including its organizational aspects. Another interesting current activity is the programme launched by the European Cancer Organisation and the European Oncology Nursing Society on the evaluation of the role of nursing on cancer care and the analysis of different countries as comparative case studies to assess the evolution of the nursing role in the EU.

The need for system-level guidance on comprehensive cancer control

The role of the CanCon Guide

Given all of the ongoing scientific activity and clinical advances related to cancer, it is important to situate CanCon's effort to create the European Guide for Quality Improvement in Comprehensive Cancer Control among other work. Cancer control is not a topic that lacks input from different sources: it is inundated with guidance and recommendations from numerous perspectives and vantage points, including patients, families, clinicians, health care managers, health system leaders, researchers/scientists and policy-makers. While there is an abundance of clinical guidance directed to cancer care professionals – the clinicians and care providers who work with cancer patients on a daily basis – the key guidance gap is on how policy-makers and leaders of cancer control agencies can use available levers to support and facilitate the achievement of optimal performance within prevailing political, economic, social and technological constraints of the broader health care system and jurisdiction. There is a need for health system guidance that addresses key elements of comprehensive cancer control, including organization/governance arrangements, financing arrangements, delivery arrangements (including human resources, technology resource planning, allocation/distribution), all within the span of control of policy-makers and cancer control organization/agency leaders *(21–23)*.

Given this target audience, other forms of guidance do exist. For example, cancer control plans are a widely used form of guidance for cancer control systems. Most high-income countries have a cancer control plan or strategy document that outlines high-level objectives for improving various elements of cancer system performance across the continuum of care *(24,25)*; this is ideally linked to regular surveillance and monitoring of system performance. However, cancer control plans do not typically aim to provide guidance on implementation nor is there sufficient other system-level guidance for cancer control. The CanCon Guide aims to help policy-makers and cancer organization/agency leaders understand the research, contextual and experiential evidence base from which to guide implementation of improvements to key elements of cancer control.

Four areas of focus

The CanCon Guide targets four distinct but related areas of focus, discussed in detail in Part II: cancer screening (Chapter 4), CCCNs (Chapter 5), community-level integrated cancer care (Chapter 6) and cancer survivorship and rehabilitation (Chapter 7). The Guide is structured to link these four areas of focus both practically and aligned with an overarching trajectory of cancer control from prevention to palliation. This begins with a focus on cancer screening, which clearly sits in the prevention sphere and is typically built upon organized and structured programmatic approaches that touch on many elements of health care systems. The second seeks to establish CCCNs through improved coordination and integration of cancer control treatment centres within health care systems. This sets the stage for focus on community-level cancer care, acknowledging the extension of care and services for cancer control from oncology-specific settings to more general primary care settings. The final and closely related area of focus is cancer survivorship and rehabilitation, representing an area of intense change and development that acknowledges cancer control successes and emphasizes the implications of the increasingly chronic nature of the disease.

Overall, these four areas of focus, while not an exclusive set, do represent big topics and tough challenges that are not consistently prioritized and that reflect a mix of solutions with varying resource needs. The CanCon Guide offers the opportunity to explore and compare different cancer control system perspectives to look for commonalities and differences. The intent of the Guide is to contextualize the challenges and distil key lessons learned for policy-makers and cancer control organization/agency leaders across Europe, flagging opportunities for action and highlighting potential successes that can be achieved.

Summary of Guide recommendations

Part II of this book provides an in-depth description of the approach and methods taken for each of the four areas examined, a review of the available evidence and the rationale supporting the recommendations made. For brevity, only the summary recommendations for each of the four areas of focus are provided in Box 2.1.

Box 2.1 Cancer screening

Policy recommendations on governance, organization and evaluation of cancer screening

Governance of cancer screening

1. Successful evidence-based cancer screening needs a competent, multidisciplinary and transparent governance structure with political, financial and stakeholder support.

2. The legal code should provide a specific framework for population-based cancer screening, enabling as a minimum the following basic functions: personal invitation, mandatory notification and central registration of complete screening and outcome data and individual linkage to cancer and cause of death registries for appropriate quality assurance including audits.

3. Successful implementation of effective cancer screening programmes requires significant resources for quality assurance, that is 10–20% of the estimated total expenditure of a full-scale programme.

Organizational requirements

4. Implementation of population-based screening should be a carefully managed multistep process through the phases of coordinated planning, piloting, rollout and continuous improvement.

5. The mandate and resources for screening coordination and training, and for the electronic information systems necessary for quality assurance and incremental improvement, must be secured before starting the population-based screening service.

Integrated evaluation

6. To secure the benefits of screening, routine linkage between the registries containing relevant data for defining the population, performance and outcome is essential and can be considered an ethical requirement of screening.

7. Whenever relevant, evaluation and regular monitoring of cancer screening should also detect social inequalities and trigger research and interventions on improved equity in health. Research collaboration has an added value to develop interventions and solutions in the local settings where social barriers and social inequalities in cancer have prevailed.

8. Benefits and harms of screening need to be clearly communicated to the public; a scientific consensus on the appropriate estimation method and estimate would be of great value as the appropriate balance may be judged differently by individuals.

9. The cost-effectiveness of a programme or a specific modification of it should be evaluated prior to deciding on the full implementation. Member States should define a threshold value for decisions on cancer screening, considering affordability and available resources.

10. Indicators for quality and effectiveness based on most recent evidence-based reviews should be monitored and acted upon regularly by updating the screening programme.

Potential new cancer screening programmes

11. Quantitative estimates of the benefits, harms and cost-effectiveness of possible new cancer screening programmes are needed to decide on implementation. It is essential that the EU Member States finance randomized trials designed to produce information necessary for policy-making and investments are needed so that results become available in as early phase as possible.

12. Active European research collaboration and pooling of results from randomized controlled trials and related health-economical assessments are necessary in order to obtain evidence relevant for the different settings, with potential variations in the burden of disease, health priorities, effectiveness, resources and affordability found among the European countries.

Comprehensive cancer control networks

Confronting the problem of inequality in cancer care

1. We recommend in order to reduce travel distance to quality cancer care, one of the many cancer care inequalities, access points and patient pathways should be clearly defined, access points are as close as possible to where patients reside and that uniformly optimal care be provided as close to home as possible.

Structure, infrastructure and governance of a CCCN

2. We recommend that a CCCN be a multicentric complex, combining units dealing with the management of all aspects of cancer care. These units will be in different locations and under a single governance structure. They will undertake to collaborate consistently in a structured way, in order to pursue their common goal with greater effectiveness and efficiency.

Care of cancer patients in a CCCN

3. We recommend that a CCCN adopts a multidisciplinary personalized approach based on tumour management groups integrating specialized hospital care with care in the community, palliative care, psychosocial support, rehabilitation and survivorship care plan.

4. Quality of care within the CCCN should be measured with quality indicators. A process for continuous quality improvement should be put in place and implemented.

5. For each type of rare cancer, we recommend identifying within a CCCN which unit if any can provide the necessary expertise. If for a certain cancer no suitable unit can be identified, the patient should be referred to an appropriate unit outside the CCCN.

Cancer research in a CCCN

6. We recommend that a CCCN takes full advantage of the proximity of patients, researchers and care providers to pursue high-value basic, translational, clinical outcome and population research programmes to fully support the delivery of optimal patient care within the CCCN.

Decision-making process for creating a CCCN

7. Given the benefits that a CCCN can provide with respect to equity of access as well as quality of cancer care, it is recommended that the creation of one or more CCCNs is always considered in decision-making. When in a certain area a CCC already exists, a CCCN can be built based on it. Performance indicators and evaluation models should be defined from the outset of the network.

Community-level cancer care

EU policy recommendations for quality improvement in cancer after-care at the community level.

1. Manage cancer as a continuous process where patients pass (transit) different phases and stages. This can be achieved through the creation and updating of a cancer patient pathway going from screening outcomes through diagnostics and treatment to long-term monitoring in remission, life-prolonging treatments and palliative and end-of-life care.

This should:

(a) reflect the current level of knowledge in cancer treatment but also the specifics of the country's health care system and its organization;

(b) secure the necessary resources – human, financial, equipment and medicines – at all stages of the pathway;

(c) develop the segment of the pathway for the cancer patients' after-care in close collaboration between specialized oncological care and primary care providers; and

(d) organize an information exchange platform that enables all providers involved in cancer patient care to share the data and files relevant to the patient.

2. An obvious need for coordination and organization through the creation of multidisciplinary teams at all levels and in the development of a survivorship care plan.

3. Dynamic coordination and flow of information between the oncological specialized care and community care, necessary for the following reasons:

(a) the proper organization of seamless care when patients move between levels;

(b) mutual exchange of information concerning both the patient's condition and disease before cancer as well as specifics of the cancer treatment, including side-effects, disabilities and long-term effects;

(c) the management of a proper uniform patient file bearing all the relevant information; and

(d) the assessment of the long-term patient needs for community care related to monitoring of cancer in remission.

4. Organization of education and training for primary care providers. This is needed in order to strengthen providers' capacity to cope with the increasing population of cancer patients in after-care.

5. Development of guidelines and guidance, at least for each of the most frequent cancers, on what to include and on what not to include in long-term monitoring of patients (system specific, differences in access to some tests and diagnostics), to include the following segments:

(a) recurrence detection, indicating the best frequency to perform diagnostic tests to detect cancer recurrence; the description of the signs and risk of recurrence in a given category of patients; and, finally, recurrence detection defined and elaborated for patient after-care in terms of the responsibilities of GPs (in case they are willing to perform this role);

(b) long-term effects of cancer with more information on the potential complications of individual types and locations of cancer and how these should be prevented and treated; more knowledge and recommendations on psychological support for cancer survivors are warranted; and

(c) recurrence prevention, with more research into the value of recurrence prevention and specific recommendations for cancer survivors.

6. Coordination between the health and other sectors for many patients, not only for those that become disabled or are terminally ill. Treatment itself, long absences from work or treatment away from family may raise all sorts of problems (e.g. additional expenses or less of productivity).

Cancer survivorship and rehabilitation

Policy recommendations for quality improvement in cancer survivorship and rehabilitation for EU Member States.

Medical follow-up: focus on late effects and tertiary prevention

1. An early and personalised follow-up programme should be systematically planned and delivered to each survivor:

(a) adequately assessing the survivors´ individual risk of multidimensional late effects of treatment and respective rehabilitation needs (e.g. physical, psychological, social, cognitive, sexual, nutrition); and

(b) creating opportunities for socially disadvantaged people to fully engage in follow-up programmes.

2. Adequate and updated information on medium and long-term effects of treatments should be available:

(a) to survivors and their relatives; and

(b) to care providers involved in the follow-up, in particular primary care professionals, for better prevention and care.

3. Identification and management of late effects of cancer treatment should be integrated in the professional training and continuous medical education of clinicians (including GPs).

4. In tertiary prevention, self-management should be emphasized, particularly on lifestyle recommendations and on the risks of long-term effects:

(a) smoking cessation;

(b) weight control and healthy diet including limited alcohol consumption;

(c) sufficient sustained physical activity;

(d) avoidance of excessive exposure to ultraviolet radiation; and

(e) stress management.

5. Physical activity should be integrated early in the care pathway for all cancer survivors. It should be an important component to consider at every phase of survivorship care for all survivors in order to maintain healthy lifestyle.

6. Evaluation of physical and psychosocial rehabilitation needs should first be screened as follow:

(a) baseline screening should be performed prior to the start of any cancer-specific treatment;

(b) both physical and psychosocial screening should be carried out simultaneously by using simple algorithms; for physical screening, at least the following items should be screened: cardiac function, muscle strength and flexibility; for psychosocial screening, see item 8 below; and

(c) after the first screening, regular updates should be performed on individual basis.

Needs for a person-centred approach in psychosocial rehabilitation, supportive and palliative care

7. Periodic screening of psychological distress and psychosocial needs should be conducted:

(a) during the entire cancer pathway by the health care professionals (e.g. oncologists, physicians and nurses) and integrated in routine cancer care; and

(b) screening should be followed by adequate provision of psychosocial care.

8. For the diagnosis of psychological conditions a specific assessment should be carried out by a psychological care professional:

(a) using validated and simple tools and according to clinical practice guidelines for the assessment and management of psychological distress and morbidity; and

(b) anticipating the specific needs of populations at high risk, including young populations (e.g. children, adolescents, young adults) and relatives.

9. A step-wise or tiered model of psychological care is recommended depending on the level of distress, psychological condition and morbidity of each patient, with interventions ranging from:

(a) information and psycho-education by primary oncology team to peer support;

(b) e-health platforms for psychosocial support and self-management programmes;

(c) Psychological interventions by professionals trained in psycho-oncology (e.g. psychologists, social workers, psychiatrists);

(d) complementary spiritual support by chaplains and others; and

(e) psychotropic treatments by trained physicians (e.g. psychiatrists, oncologists).

10. Psychosocial interventions in individual or group format should be delivered by appropriately trained professionals with specific expertise in psychosocial oncology.

11. Increased investment in training in psycho-oncology and communication skills for primary oncology staff is highly recommended.

12. Existing clinical practice guidelines for psychosocial support of patients with cancer could be highly valuable and recommended for the provision of evidence based psychosocial care.

13. Social and return-to-work issues should be integrated early into the cancer care pathway. Adaptation of working conditions for any patient returning to his/her previous work should be assessed at early stages.

14. Public policies should be developed and implemented to support cancer patients from diagnosis to return to work including:

(a) financial aspects such as access to loan, mortgages, life insurances;

(b) implementation of a pan-European strategy to tackle the differences between workers with cancer in different countries and to prevent discrimination; and

(c) generatation of more evidence to better understand the living conditions of cancer survivors who return to work.

15. A person-centred approach should be implemented:

(a) to access a multidimensional physical and psychosocial rehabilitation plan focusing on the skills of cancer survivors;

(b) to safeguard cancer survivors' working lives; their employability, competencies and capacity to work, as well as their motivation to work; offer new skills to self-employed workers to help them to achieve balance between health needs and work;

(c) to involve peers, patient organizations and trade unions to help patients and survivors; and

(d) to negotiate a patients' bill of rights, including the right to work with special conditions (e.g. reduced hours of work or adapted working conditions).

16. A work-centred approach should be implemented with a better involvement of employers in survivors' return-to-work process:

(a) to explore possibilities of changes in job function for cancer survivors and to encourage them to acquire new skills;

(b) to facilitate the implementation of flexible working hours and options (remote working, part-time work); and

(c) to offer economic benefits to employers who agree to adapt the workplace to the needs of cancer survivors and to help self-employed workers to adapt their workplace and business to address health needs.

17. Somatic and psychological symptoms as well as social challenges should be addressed in all phases of the cancer disease trajectory early, systematically and regularly.
Treatment should be according to the best scientific evidence available.

18. Formal education in palliative care should be a compulsory component of the professional curriculum for specialists in medical oncology, for GPs and community clinicians:

(a) basic training should be mandatory in medical and nursing schools; and

(b) specialized palliative care skills and services should be accessible to patients with advanced incurable disease and part of multidisciplinary tumour boards.

19. Best achievable quality of life for the individual patient and the relatives should be part of a survivorship care plan for patients with late side-effects from cancer and antineoplastic treatments.

Multidisciplinary approach in survivorship care: coordination of providers and empowerment of survivors

20. Psychosocial care, rehabilitation and palliative care should be integrated into the entire cancer pathway including the survivorship and rehabilitation period. Psychosocial, rehabilitation and palliative care specialists should be members of (or associated with) the medical team in hospitals and in community care.

21. After the completion of the acute treatment phase, the follow-up period should begin with the elaboration of a survivorship care plan.

22. The role of GPs and other primary care professionals should be actively supported to help them to manage all the care plan challenges:

(a) their role should be clearly defined and tailored to the patient and the care plan needs; and

(b) this role could evolve during the follow-up period.

23. Communication between primary health care providers and health care specialists needs to be improved:

(a) electronic patient records systems should be accessible to all health care providers treating the patients; and

(b) communication between patients and health care providers should be improved.

24. A key health care professional assuming a case management role should be assigned to each patient in accordance with medical and/or psychosocial specific requirements. This health care professional could play a main role in reducing the vulnerability of the patient, for example with the management of adverse drug effects.

25. Empowerment of patients and their relatives should be enhanced to increase their participation in self-management, rehabilitation and back to work programmes. Online programmes would facilitate this process.

26. Education and self-management programmes should be developed and evaluated:

(a) better access to these programmes should be available for underserved and deprived populations (low income/low education);

(b) assessment of patients' needs should be systematically part of the development of an education programme; and

(c) evaluation of these programmes should assess the impact on the personal, organizational and health care policy levels, including cost-effectiveness and impact on health care quality.

27. Training of health care professionals should include communication skills alongside medical education:

(a) regarding information/communication/knowledge of survivorship and rehabilitation needs; and

(b) management of late effects.

Childhood, adolescent and young adults issues in cancer survivorship care

28. **Transition of care from pediatric oncology to adult medicine,** including a survivorship passport for each patient, should be organized to guarantee adequate long-term follow-up and setting up appropriate intervention *(26)*.

29. **It is necessary to aim for a more efficient survivorship care planning and coordination to respond to the challenges of the prevalence of chronic conditions, health status deteriorations, treatment and complex prevention.** Determining the most effective models of care for childhood cancer survivors is the main step forward.

30. **Rehabilitation and supportive care should be specifically offered to children, adolescent and young adults as cancer survivors,** in particular adapted physical activity. A routine yearly psychosocial assessment with attention to social, psychological, and behavioral issues, educational and/or vocational progress should be provided to this population.

31. **End-of-life care and palliative care for children and adolescents should be improved across Europe.**

Perspectives in survivorship and rehabilitation cancer research

32. **An information and data collection system focused on late adverse effects (physical, psychological, cognitive, social, sexual), coupled to the surveillance of patients and involving primary care professionals, should be set up.** More patient-reported outcome measures and their routine use are needed.

33. **Use of cancer registries to collect data on survivors would produce stronger epidemiological data, including lifestyle, quality-of-life or socioeconomic information:**

(a) to better identify the causes of inequalities in survivorship;

(b) registries should be expanded to include additional factors that influence the quality of life (e.g. rehabilitation and employment issues);

(c) patient reported outcomes could also be a way to collect appropriate information.

34. **Clinical research should evaluate the feasibility, the efficacy and the cost-effectiveness (including the economical dimension) of non-drug-related interventions such as self-management and e-health programmes.**

35. **Future research is needed to establish a multidimensional rehabilitation model focused on the quality of life and the coordination of complex care to better address the management of late effects across the whole survivorship trajectory.** More research would also be required to maximize the long-term follow-up and care of childhood cancer survivors and to identify the genetic risks associated with late effects and second cancers.

36. **More solid methodological randomized controlled trials and cohort studies are needed in order to reduce the intensity of cancer treatments while maintaining their efficacy and thus reducing the probability of late effects, especially in childhood cancer survivors.**

Appraisal of the Guide recommendations

The specific recommendations for each of the four areas of focus highlighted above are detailed in Part II. In the remainder of this chapter, comment on the methodological approach taken is presented, as well as consideration of common themes across the four areas of focus and identification of some key gaps that this Guide has not addressed.

Comment on methodological approach taken

As the CanCon experience reveals, it is not easy to get a broad collection of stakeholders from many different countries to pursue similarly rigorous methodological approaches that can yield useful insights to guide policy and practice. Yet, at the same time, the act of coming together and discussing important issues in earnest can lead to invaluable insights and shared learning. Evidence for policy cannot rely solely on research evidence, but also requires contextual evidence (e.g. measurable information and characteristics related to geography, sociodemography, system/organizational structure/capacity and economic, cultural and political factors) and experiential evidence (e.g. tacit knowledge and collective professional/practical insight and expertise) *(27)*. The intent of the CanCon approach was not to rely exclusively on rigorously conducted systematic reviews of research literature, but rather to have work package teams that would combine reviews of relevant literature with assessment of experiential and contextual evidence, drawing on team members' knowledge of contextual factors that influence country-specific situations. Overall, a main intent of the Guide is to draw on the comparative experience of the participating European countries and cancer systems to provide guidance on the four areas of focus.

Common themes and gaps

There is in-depth consideration of each of the four areas of focus and their respective recommendations in Part II of the Guide. The Guide's 62 recommendations across the four areas of focus required consideration of the perspective of the target audience – policy-makers and cancer organization/agency leaders – and their overarching responsibilities to assess the common themes that have arisen from this work and key gaps that may represent areas to target for future work.

The system level and the need for improved coordination/collaboration

Although quality improvement is part of the title of the Guide, emphasis on quality improvement is subtle throughout. Quality improvement typically references clinical contexts and efforts but the focus of the Guide is more aligned with broader improvement science and emerging thinking on health system strengthening. The system level received a lot of attention, but the main elements of health systems (e.g. understanding and improving governance and financial arrangements and the structure and organization of service delivery) were not consistently addressed by each area of focus. Despite the lack of consistency, there was considerable attention throughout the Guide on system-strengthening components. The cancer screening recommendations did, in fact, comprehensively cover governance, financial, and service delivery arrangements, while recommendations for integrated cancer control were orientated towards policy-makers and directly addressed governance arrangements and decision-making processes.

The cancer survivorship/rehabilitation and community-level cancer care recommendations focused mostly on service delivery arrangements. Much of this relates to how providers can work together in more coordinated and collaborative ways, including improving how patients transition from provider to provider and care setting to care setting. Throughout the Guide, there are repeated calls for greater multidisciplinary work and interprofessional collaboration among different levels of care and for multicentre work beyond the health care sector. This should be a key overarching focus for policy-makers and cancer organization/agency leaders to accentuate. However, while integrated cancer control is clearly a prominent focus for the Guide, there is more work needed to understand the nature of existing networks of cancer control organizations and the potential requirements for establishing a more comprehensive network for cancer control within varying health system contexts.

Being at the frontline of cancer control means tackling increasing and interconnected challenges and areas of care (e.g. survivorship and quality of life; psycho-oncology and genetic counselling) that require the development of multistakeholder strategies when formulating and implementing new approaches and actions on cancer care. Importantly, the EU through CanCon and EPAAC has become a reference for thinking on those approaches where the impact is expected to be meaningful, tackling the broader patient needs along the continuum of care.

The patient perspective

Three of the Guide's four areas of focus gave considerable attention to the patient perspective, consistent with the patient-centred approaches that have begun to dominate health systems thinking since the early 2000s. Recommendations for cancer survivorship and rehabilitation and for community-level cancer care emphasize the importance of self-management and the patient pathway, while the integrated cancer control recommendations were centred on the need to make access for patients more equitable. Only the cancer screening recommendations did not address patient-specific issues directly. The consideration of the patient perspective is a key theme of the Guide and a prevailing theme of health systems generally, and patient organizations, such as the European Cancer Patient Coalition or the European Cancer League, are key contributors to improving cancer control. Policy-makers and cancer organization/agency leaders can influence the potential of patient-oriented approaches to advance cancer control by establishing and reinforcing patient organizations as a core strategy.

Research and information

Unsurprisingly, another set of common themes in the Guide relates to the need for research and information on cancer control. Research is needed in many areas, from basic and applied research to clinical data systems to system-level performance measurement/reporting to detailed assessment of health system contexts. A previous European effort (EPAAC) targeted research and cancer information needs, particularly related to clinical settings and health outcomes; however, there is a notable need for targeting research and information investments on the system level. Each of the Guide's four areas of focus include recommendations for better coordination and collaboration on research and/or information sharing to support improved cancer control. An underlying emphasis for greater collaboration and coordination on research and information sharing reflects both efficiency and effectiveness needs. The cancer screening recommendations, for example, include the need for collaboration to efficiently produce high-quality evidence from randomized controlled trials (RCTs) that takes account of changing incidence of disease (e.g. the consequences of immunization for human papilloma virus (HPV). The cancer survivorship and

rehabilitation recommendations encourage improvements to health informant technology and electronic health records, while the community-level cancer care recommendations comment on the importance of information sharing and long-term monitoring. As the push for more integrated approaches to cancer control evolves, the need for shared information sources, both within and across health systems, will only continue to grow.

While the Guide emphasizes research and information-sharing needs, there is limited specific focus on performance measurement and reporting at multiple levels (e.g. clinical, health services and systems, population health). Given the importance of the four areas of focus covered in this Guide, there is a corresponding need to deliberately advocate and direct the development of performance measurement capacity related to these areas. This includes development of common sets of performance indicators, benchmarks and approaches to target setting that address the recommendations put forward in this Guide. Furthermore, performance measurement systems are particularly useful in identifying promising practices that can be shared across systems and jurisdictions.

The Guide is not accompanied by detailed country-specific information on the cancer control and health system context. Country contexts and health system features can influence the nature of a specific cancer control problem. Understanding of the challenges may be specific to the country, given the relative emphasis/focus on the problem and efforts to monitor and evaluate the effects, develop and implement solutions. For example, it has been shown that the coverage and variables collected for population-based cancer registries vary widely across different countries in Europe *(28)*, affecting assessments of the feasibility and impact of cancer plans and interventions. While contextual and experiential insights are implicitly addressed through the multicountry participation for each area of focus, some of this context-specific information that underlies the recommendations may not be apparent to interested system stakeholders. As part of aims to enhance performance measurement capacity, there is an opportunity to contribute to more detailed contextual analyses of the system features relevant to cancer control systems in order to facilitate interpretation of country-specific efforts and their transferability and applicability to other jurisdictions.

Resource needs and the economic rationale

The Guide provides 62 recommendations but demands for new resources are mostly muted, largely reflecting the economic context within which this work has been produced. While there are some specific requests for investment (e.g. training of clinicians in survivorship and rehabilitation), the Guide puts a very limited economic analytic lens to the recommendations. While beyond the scope of the current Guide, understanding of and insight on opportunity costs of the recommendations are critical. Injecting economic evaluations to more clearly distinguish the needs from the wants represents an important opportunity to extend the value of the Guide to give policy-makers and cancer organization/agency leaders the type of information needed to establish sound value propositions for investment decisions.

Impact of non-health sectors

Another theme that was emphasized by two areas of focus in the Guide addressed the need for coordination and collaboration with non-health sectors. Both community-level cancer care and cancer survivorship and rehabilitation recommendations emphasized the role that non-health sectors/stakeholders (e.g. social/employment policy-makers, banking/mortgage agencies, life insurance providers) can have on the well-being of those who survive cancer. Health policy-makers

and system-level leaders are uniquely positioned to facilitate interaction with non-health sector stakeholders. While experience suggests that it is quite a challenge, the Guide's recommendations illustrate the important need to support interactions with non-health sectors and represent an area where health policy-makers can provide crucial additional value to cancer control efforts.

Cancer control opportunities

As previously noted, cancer control is a complex and challenging topic. This Guide intended to target policy-makers and leaders of cancer agencies/organizations on ways to improve cancer control from a health systems perspective, with four work packages directing focus towards four key topics: cancer screening, integrated cancer control, community-level cancer care and cancer survivorship and rehabilitation. These four key areas of focus for comprehensive cancer control have yielded 62 recommendations that need to be pursued. Appraisal of these recommendations also highlights a number of key gaps that were not directly addressed through this work but represent future opportunities to improve cancer control in Europe.

Ultimately, the Guide needs to inform and direct its target audience – policy-makers and cancer organization/agency leaders – as much as those actively involved in the provision of cancer care day-to-day to take action. However, the 62 recommendations can read both like a comprehensive assessment and a somewhat bewildering starting point for improving cancer control. The key opportunity going forward is to make the 62 recommendations in the Guide actionable at the level of national cancer plans without missing the European-wide perspective. The CanCon perspective shows that it is feasible to learn from country-specific experiences, as is detailed in several of the following chapters of the Guide, and to combine these experiences to generate an opportunity to progressively build European cancer control policy. This approach, combining both national and a broader European perspective, can complement parallel initiatives, such as the European reference networks or the oncopolicy perspectives proposed by different scientific societies or patient organizations, such as EURORDIS, Rare Diseases Europe, the European Cancer League or the European Cancer Patient Coalition.

To operationalize the Guide's recommendations for the advancement of comprehensive cancer control, there are a few key questions that should be put pursued. In the prevailing zero-sum investment context, which recommendations are the clear priorities? Who, specifically, should each recommendation be directed to in order for tangible action to be taken? What needs to be done to monitor those efforts and the potential results?

The demands on cancer control are not going away and will only grow more challenging. The recommendations outlined in this Guide represent an important step in preparing our health systems for the evolving challenges. Enthusiastic contributions from our diverse CanCon team have been a crucial part of the valuable CanCon experience; we encourage continued collaborations with patients, clinicians, health care managers, researchers and other stakeholders from across Europe to help to operationalize the shared lessons learned and advance comprehensive cancer control.

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