

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

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Introduction

What is cancer after-care? Cancer after-care is the period when care is provided to patients who are in remission and have completed the planned disease-specific oncological care. They are monitored for recurrence and late effects of treatment but can be generally classified as cured. The modalities of organization of this care differ largely across countries and may be through arrangements in hospitals and their outpatient departments, through community care providers or in a combination of the two.

One of the important positive effects and challenges associated with recent advances in cancer treatment has been the constant rise in the number of cancer survivors. These might be patients who are in long remission periods as well as patients who are receiving life-prolonging treatments. Increasing incidence and prevalence of cancers, through the ageing population and the increase in some risk factors (e.g. obesity, physical inactivity) is leading to an increasing demand for oncological care closer to home. Consequently, the importance of coordinating processes and patient pathways in cancer care across levels of care has been increasing. Grunfeld and Earle stressed the importance of “transitions”: from focus on diagnosis and treatment to long-term follow-up care, management of late effects, rehabilitation and health promotion (1). Throughout these transitions, collaboration between oncologists and GPs is crucial. This collaboration can be challenged by variable interest, poor communication with GPs and patient preferences for follow-up (2). The last issue also relates to differences in health systems and organizational preferences arising from a specific health care system (e.g. strong stress on hospital and specialist care, free access to specialist, low profile for PCPs).

After-care was traditionally in the hands of cancer centres and hospitals treating cancers. Increasing incidences, ageing of populations, increased complexity of the initial phases of cancer care and changing patterns of care at the community level now pose a challenge and the need to place an important share of cancer after-care in the hands of PCPs. One of the challenges arises from the

costs of oncological care within cancer centres or specialized hospital departments. In addition, intensification of oncological care, particularly at the level of medical/clinical oncology, has meant focusing time and efforts on patients receiving treatment, to the detriment of the after-care phase. A further consequence is that after-care is less well defined and, most importantly, less structured. Cancer patients also face social challenges – loss of work capacity, rehabilitation, disability and/or mental problems – which all require a comprehensive psychosocial approach close to a patient's living and working environment. In view of these challenges, structured development of (new) pathways should ideally encompass the transfer of cancer after-care into community care settings along with adequate training of all health and social care professionals involved in the process. Proper reallocation of tasks is necessary in order to secure an adequate quality of care, its continuity and a seamless process, as well as for maintaining a high level of patient trust and cooperation. In addition, most cancer patients are older and very often have chronic diseases before their cancer diagnosis, particularly cardiovascular diseases, diabetes or a neurological problem. Cancer survivors have different types of need that may be insufficiently met by general practice (3).

Two further terms need explanation and clarification with respect to the context in which they are used throughout this chapter – primary care and community care. It was decided to use the term community care as it encompasses the wider range of services necessary for any patient with a chronic condition. These services go beyond the immediate care delivered within health care and are specific in cancer patients because of the range of outcomes, including long remissions and cure. Community care also needs to address social, economic, employment, financial and spiritual needs of patients, which arise either from the longitudinal nature of the disease or from the consequences of the treatment and their impact of the patient's daily life, economic, employment, social life and other activities. Care of patients at the community care level will be explored as a challenge in changing health systems where rational approaches should ideally meet with patient preferences.

This chapter focuses on the organization of after-care and supportive care for patients, predominantly outside of specialized oncological care. The latter normally encompasses the specialized and focused curative treatment that is prescribed based on a baseline assessment of the patient's disease. Once in remission and classified as without active disease, patients mostly return to their lives before cancer. Nevertheless, this phase and period pose different challenges, both for the patient and for health care services at the community care level. Chapter 7 will focus on patient experiences and will deal with the first group of challenges through an analysis of the current state in this field as well and by proposing a survivorship care plan. Here we explore the organizational and process aspects of the organization of cancer after-care for those patients who require further interactions with community and social care because of their cancer treatment. The chapter does not generally include patients requiring palliative and end-of-life care apart from the case study of Norway, where care for this group of patients is inseparably connected to the organization of after-care. The organizational framework provided by the health system is also one of the important levers to secure equitable access to necessary services, attempting to avoid any increase in differences among patients based on social, geographical, gender or other characteristics. The ambition here is to draw attention to this specific segment of cancer care in order to:

- define after-care for cancer patients better, including the different services (as required by patients and their needs) and the organization of community care for these patients, their spouses or significant others, carers and families;

- outline how after-care is organized in certain European countries and highlight positive experiences; and
- argue for the need to structure and carefully plan the *entire* span of the cancer patient pathway including after-care, with full support in terms of adequate resources.

The chapter presents an inventory of what information on after-care is available for GPs as their role expands and an overview of national and regional practices on how the phase of cancer after-care is organized in Bulgaria, Denmark, the Netherlands, Norway and Slovenia. Four of these countries have a GP gate-keeping system and a strong role of community care, including in the cancer after-care process. Only in Bulgaria does after-care remain the task of cancer hospitals. Based on these findings, we will draw tentative conclusions, which will translate into draft policy recommendations for the future development of patient pathways for cancer after-care and its management in community care settings.

Methods

This chapter describes the analyses done within CanCon and incorporating findings of previous, current and ongoing research. Five European countries – Bulgaria, Denmark, the Netherlands, Norway, and Slovenia – were actively involved in its development by virtue of their participation in the project. The countries presented in this chapter were included given the interest of their respective ministries of health in participating in the project. This is, therefore, self-inclusion and not a systematic and structured involvement of specific countries. Following the self-inclusion, the methodologies used in the different countries in order to substantiate some specificities of their after-care process, the relationship between levels of care and the relationship between central and regional activities vary greatly. Consequently, there was no overall harmonization of methodologies.

A short description of the methods is provided here, while a detailed description can be found online (supplemental information provided at www.cancercontrol.eu).

Given the diversity of country cases and the respective foci of their research, a series of methods were used for data collection:

Survey of experts and country informants

A survey of experts and country informant was carried out with the collaboration of national contact points: project partners, ministries of health, cancer centres and public health institutes and similar services. Experts from all EU Member States, Norway, Switzerland, Iceland and Turkey participated in identifying guidelines as well as providing national or regional guidelines that included relevant information for GPs.¹ Experts from 12 countries (Czechia, Estonia, Greece, Iceland, Latvia, Luxembourg, Malta, Slovenia, Slovakia, Sweden and Turkey) indicated that there were no tumour-specific guidelines containing information on after-care relevant to GPs. The remaining

¹ Delegates from national primary care associations, nurse associations, universities with a medical department, the Cancer and Primary Care Research International Network, the European Forum for Primary Care, the European Society of General Practice/Family Medicine and CanCon collaborating and associated partners. Forty-five experts corresponding to all 32 approached countries provided filled-in questionnaires (supplemental information provided at www.cancercontrol.eu).

experts indicated that there was at least one tumour-specific guideline. Despite multiple efforts, eight experts from seven different countries, who had indicated that their country had tumour-specific guidelines, did not provide any guideline. In total, 77 guidelines were received and 47 were deemed relevant. In databases and on web sites, 48 additional relevant guidelines were found. Literature review of existing guidelines on after-care for breast, colorectal, lung, melanoma and prostate cancer survivors focused on the relevance of guidelines for GPs. International guidelines were collected via searches on the Internet and in literature to create a more complete overview of guidelines. Databases Embase and Medline, the National Guideline Clearinghouse (4) and the Guidelines International Network (5) were searched using the terms "guideline", "breast cancer", "colorectal cancer", "colon cancer", "rectum cancer", "melanoma", "lung cancer", "prostate cancer". In addition, cancer agency web sites were accessed for relevant tumour-specific guidelines.

A category and topic list per tumour type was composed after assessing all guidance on after-care. The objective was to establish uniform categories and topics for the various tumour types. Several categories for the purpose of this study were defined: recurrence detection, long-term effects and recurrence prevention. The category and topic list can be found online (supplemental information provided at www.cancercontrol.eu). An important element was awareness, which means awareness of patients to potential recurrence, monitoring of disease development and of signs and symptoms of the disease. Guidance considered relevant was summarized into topics independently by two researchers. If guidance did not fit into the created topics or if topics became too broad, a new topic was created by discussion. Disagreements arising from decisions on scoring were resolved by discussion with a third researcher.

Exploration of cancer after-care organization and services in five European countries

In Bulgaria, the National Centre for Public Health Analyses carried out a set of structured interviews on perceptions of after-care services, in particular from the point view of the type of provider. The questionnaire was based on the one developed in the first phase of the Slovene study and was focusing on the description of the provision of cancer after-care in Bulgaria, with the volumes of care and staffing in each cancer centre; no information was collected on the actual contents of care.

For Denmark, a reform of after-care is in progress. Plans on follow-up care for each main type of cancer are under preparation. These plans should address several topics regarding cancer after-care.

For the Netherlands, NIVEL carried out a series of health services research studies (see the country study report below) and measured the impact on after-care on the volume of care in a GP practice (i.e. the perspective of the service delivery). They specifically analysed these impacts from the provider perspective, measuring the increased workload, effect on carers and on other personnel delivering community care.

The Norwegian case constitutes a health services intervention study where the activities of an ongoing transformation (the transfer of certain specialist services including palliative care to the community level) are described.

The Slovene study combined a quantitative cross-sectional survey of a stratified random sample of 250 GPs practising in Slovenia, with semi-structured interviews conducted on a purposive sample of six physicians from the Upper Carniola region. GPs were interviewed about some characteristics of cancer patients on their lists and after-care delivered to these patients. One focus of this study was the exploration of links between different services in community care and social services. Finally, good practice recommendations on after-care in GP practices were developed and tested during the study.

The selection of countries included was not intended to be representative of all EU Member States nor exhaustive. It has to be kept in mind that the exploration was not primarily research oriented, but rather seeking for good practices in the countries that participated in the CanCon project.

Results

After-care for cancer survivors: recommendations for GPs in cancer guideline

Given the growing number of cancer survivors worldwide, there are increasing calls for greater involvement of PCPs in after-care. Currently, there is only little structured information for GPs on the best way to provide after-care. Guidelines are an important source of information on after-care for GPs. Consequently, an investigation examined what information on after-care was available and (potentially) relevant for GPs in national and regional guidelines from European countries and non-European western countries (Box 6.1). An inventory of tumour-specific guidelines on the five most common tumour types (breast cancer, colorectal cancer, lung cancer, melanoma and prostate cancer) was completed because it seemed likely that GPs see those survivors most frequently, and this would create an overview of all presented guidance and advice. Other tumour-specific guidelines were reviewed to uncover additional information.

Many guidelines did not specify their target audience and so it was necessary to distinguish whether guidance was relevant for GPs. We chose to use the Dutch GP as a reference for what guidance was relevant; diagnostic tests and actions that Dutch GPs could perform were identified as potentially relevant. This included all actions that could be performed within the general practice, as well as tests that could be requested from a laboratory (blood tests) and routine screening tests where results are routinely sent to the GP (e.g. mammography). Expensive invasive diagnostic tests that hospitals normally provide (e.g. magnetic resonance imaging) were identified as irrelevant for GPs. The same applies for treatment of recurrence normally provided in secondary care.

In total, information on 95 guidelines (47 obtained via experts and 48 identified via literature and Internet searches) originating from 36 countries was extracted and summarized into topics (Table 6.1) (supplemental information provided at www.cancercontrol.eu, including a list of included guidelines and the providing countries).

Table 6.1 Number of guidelines and their focus concerning after-care guidelines and providers

| Cancer location | Number of guidelines | Countries with guidelines | No. guidelines focusing on after-care | No. of guidelines with at least one scientific reference to after-care | Guide for GPs |
|------------------------|-----------------------------|----------------------------------|--|---|----------------------|
| Breast | 24 | 19 | 7 | 17 | 4 |
| Colorectal cancer | 21 | 16 | 6 | 12 | 1 |
| Lung | 17 | 11 | 3 | 9 | 1 |
| Melanoma | 15 | 13 | 1 | 12 | 1 |
| Prostate | 18 | 14 | 4 | 14 | 1 |

Breast cancer

All of the 24 guidelines related to breast cancer recommended performing physical diagnostic tests (history and physical examination) and diagnostic imaging (mammography) but showed less consensus about the frequency. All guidelines agreed on an annual examination after five years, which reflects that most recurrences happen within five years of treatment (6). Five of the 20 recommended time intervals were evidence based. These recommendations showed nearly the same inequality in consecutive time intervals; there was only more agreement on the intervals in the first two years after diagnostic tests (every three to six months). More agreement was observed on the frequency of mammography. Nineteen guidelines recommend performing a mammogram annually (supplemental information provided at www.cancercontrol.eu). Most of the guidelines recommend check-ups every three to six months in the first three years after treatment, followed mostly by six-monthly check-ups until after the fifth year.

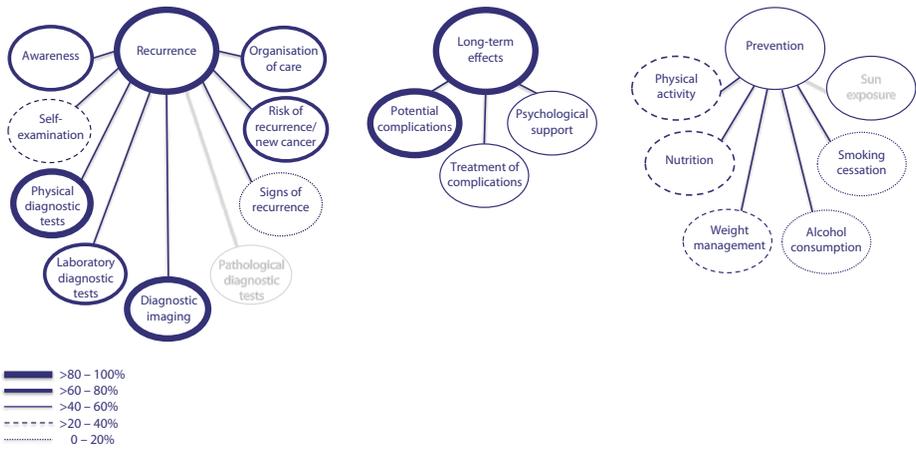
The breakdown of the different tests and procedures related to breast cancer after-care is presented in Fig. 6.1, including the weight given to the different tests. Tables 6.1 and 6.2 present the frequency of the key elements of the guidelines per number of the guidelines in which they had been identified (see above). Laboratory diagnostic tests were considered as non-routine tests. Only seven guidelines provided recommendations on self-examination by the patient.

Table 6.2 Number of guidelines on breast cancer by after-care category and number of topics dealt with per category

| After-care category | Topics dealt with |
|----------------------------|-----------------------------------|
| Recurrence detection (24) | Physical diagnostic tests (24) |
| | Diagnostic imaging (24) |
| | Awareness (15) |
| | Laboratory diagnostic tests (19) |
| | Risk of recurrence/new cancer (4) |
| | Organization of care (16) |
| | Self-examination (7) |
| | Signs of recurrence (4) |
| Long-term effects (22) | Potential complications (20) |
| | Treatment of complications (11) |
| | Psychological support (14) |
| Recurrence prevention (10) | Physical activity (9) |
| | Nutrition (5) |
| | Weight management (8) |
| | Alcohol consumption (3) |
| | Smoking cessation (2) |

Note: Total number of guidelines on breast cancer: 24.

Fig. 6.1 Overview of categories and topics on after-care for breast cancer derived from 24 guidelines

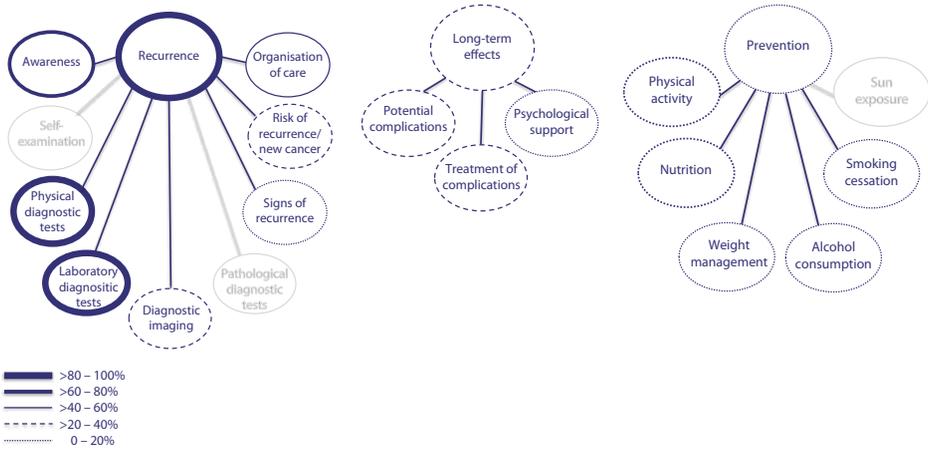


Note: Topics shown in grey were not discussed in the guidelines.

Colorectal cancer

Two guidelines were specific for colon cancer and two for rectal cancer. In total, information from 20 guidelines was used. Fig. 6.2 presents an overview of the potentially relevant categories and topics for GPs. All 20 guidelines provided information and recommendations on recurrence detection; seven topics in this category were identified. Laboratory diagnostic tests (carcinoembryonic antigen testing), physical diagnostic tests (history and physical examination), awareness and organization of care received most attention. One of the six after-care-specific guidelines discussed long-term effects such as depression/distress, fatigue and incontinence problems. Four guidelines discussed prevention of colorectal cancer recurrence and one guideline provided information on all five topics identified within prevention of colorectal cancer (Table 6.3). Guidelines agreed on the usefulness of laboratory and physical diagnostic tests, but not on the time interval between consecutive tests (supplemental information provided at www.cancercontrol.eu). The majority of recurrences occur within the first three years (7). There was high agreement to stop diagnostic tests after five years, except in one guideline. After five years, the risk of colorectal recurrence is very low; just less than 1% of all recurrences occur later than five years after surgery (8). Only three guidelines reported that the recommendation on physical diagnostic tests was evidence based. For carcinoembryonic antigen testing, the same tendency towards less frequent tests after three years was observed, while all guidelines agreeing to stop after five years.

Fig. 6.2 Overview of categories and topics on after-care for colorectal cancer derived from 20 guidelines



Note: Topics shown in grey were not discussed in the guidelines.

Table 6.3 Number of guidelines on colorectal cancer by after-care category and number of topics dealt with per category

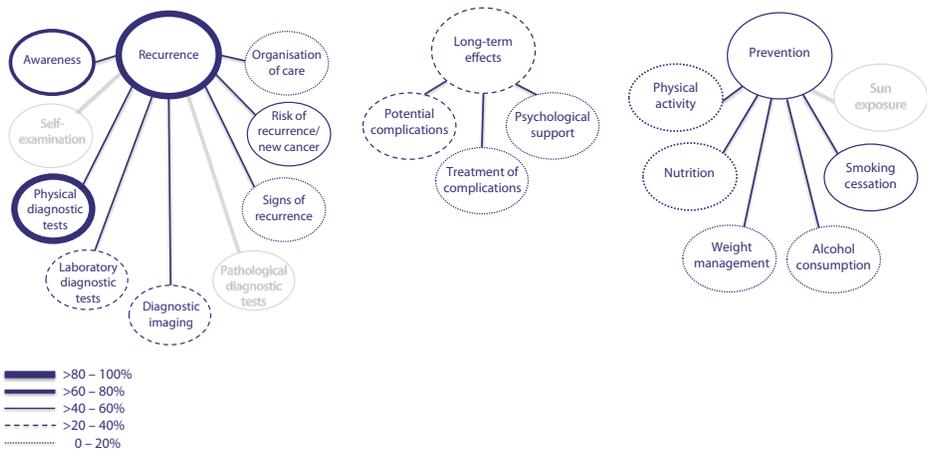
| After-care category | Topics dealt with |
|---------------------------|-----------------------------------|
| Recurrence detection (20) | Physical diagnostic tests (18) |
| | Diagnostic imaging (5) |
| | Awareness (16) |
| | Laboratory diagnostic tests (19) |
| | Risk of recurrence/new cancer (8) |
| | Organization of care (10) |
| | Signs of recurrence (3) |
| Long-term effects (8) | Potential complications (8) |
| | Treatment of complications (5) |
| | Psychological support (4) |
| Recurrence prevention (4) | Physical activity (4) |
| | Nutrition (3) |
| | Weight management (3) |
| | Alcohol consumption (2) |
| | Smoking cessation (2) |

Note: Total number of guidelines on colorectal cancer: 20.

Lung cancer

In total, 17 guidelines were used to create an overview. Eight out of 15 guidelines were on both small and non-small cell lung cancer, five were only on small cell lung cancer and two were on non-small lung cancer. Fig. 6.3 shows an overview of potentially relevant categories and topics for GPs on lung cancer, identified as present in the 15 guidelines with 15 topics. All guidelines discussed recurrence detection of lung cancer, giving information on seven topics among which physical diagnostic tests and awareness were most prominent (Table 6.4). Four guidelines discussed long-term effects of lung cancer (none of them after-care specific guidelines). The most reported potential complications were pain and loss of lung function, but only one guideline provided information on treatment of complications.

Fig. 6.3 Overview of categories and topics on after-care for lung cancer derived from 15 guidelines



Note: Topics shown in grey were not discussed in the guidelines.

Table 6.4 Number of guidelines on lung cancer by after-care category and number of topics dealt with per category

| After-care category | Topics dealt with |
|---------------------------|-----------------------------------|
| Recurrence detection (15) | Physical diagnostic tests (14) |
| | Diagnostic imaging (6) |
| | Awareness (11) |
| | Laboratory diagnostic tests (4) |
| | Risk of recurrence/new cancer (8) |
| | Organization of care (3) |
| | Signs of recurrence (1) |
| Long-term effects (4) | Potential complications (4) |
| | Treatment of complications (1) |
| | Psychological support (2) |

| After-care category | Topics dealt with |
|---------------------------|-------------------------|
| Recurrence prevention (9) | Physical activity (2) |
| | Nutrition (2) |
| | Weight management (2) |
| | Alcohol consumption (2) |
| | Smoking cessation (9) |

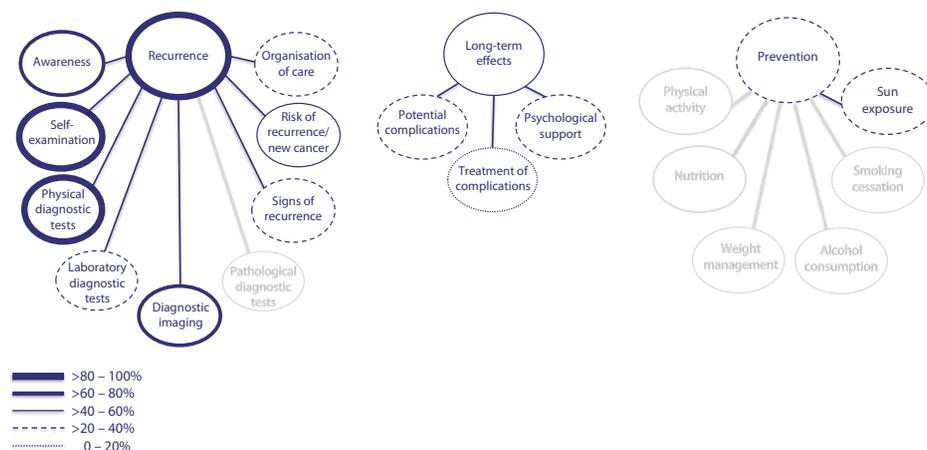
Note: Total number of guidelines on lung cancer: 15.

The recommended frequency was highest in the first year after treatment, corresponding to risk of lung cancer recurrence that peaks around nine months after treatment (9). Around 60–70% of the relapses occurred in the initial two to three years after treatment, reflected by the high frequency of follow-up during these years. In the fourth and fifth year, the risk of recurrence declines and recommended frequencies were once to twice a year. After five years, most guidelines recommended annually diagnostic tests or to stop testing as the majority of relapses occurred in the first five years after treatment. The two guidelines that reported that the recommendation on physical diagnostic tests was evidence based did not agree on time intervals between diagnostic tests. One recommended physical examination every three to six months for three years and then annually, while the other recommended performing physical examination every three months in the first two years, every six months in year three to five and then annually. This means that a uniform position is needed from oncologists in order to inform the PCP.

Melanoma

All guidelines included recommendations on recurrence detection (Fig. 6.4). Of the eight topics identified, physical diagnostic tests, self-examination, risk of recurrence and laboratory diagnostic tests received most attention (Table 6.5). Melanoma stands out among the five cancer types in that self-examination is recommended as a method of recurrence detection. Eight guidelines discussed long-term effects of melanoma, focusing in particular on psychological support but also on potential treatment complications such as lymphoedema, fatigue, fear, depression/distress and thrombocytopenia. Only sun exposure was identified within the category recurrence prevention. Six guidelines highlighted the avoidance of sunburn by reducing sun exposure and tanning use. All guidelines recommended physical diagnostic tests and 12 gave recommendations on time intervals. In eight of these, the recommended frequency depended on the stage of the primary melanoma, while four gave recommendations independent of the initial stage. As the risk of recurrence is related to the primary tumour thickness (10), the frequency of follow-up depends on the stage of the primary melanoma. There is no agreement on the time intervals between consecutive physical diagnostic tests. After 10 years, seven guidelines recommended stopping diagnostic tests, seven to continue testing and two to continue if diagnostic tests were clinically indicated. Four guidelines indicated that the recommended time intervals were evidence based. There is somewhat more agreement on the time intervals if the initial stage of the melanoma was stage II or III. Time intervals are shorter compared with stage I because the risk of recurrence is higher (11). Most guidelines agreed on three to six month time intervals in the first three years after treatment. This is in accordance with the risk of recurrence, which is highest in the first two to three years after treatment (12).

Fig. 6.4 Overview of categories and topics on after-care for melanoma derived from 15 guidelines



Note: Topics shown in grey were not discussed in the guidelines.

Table 6.5 Number of guidelines on melanoma by after-care category and number of topics dealt with per category

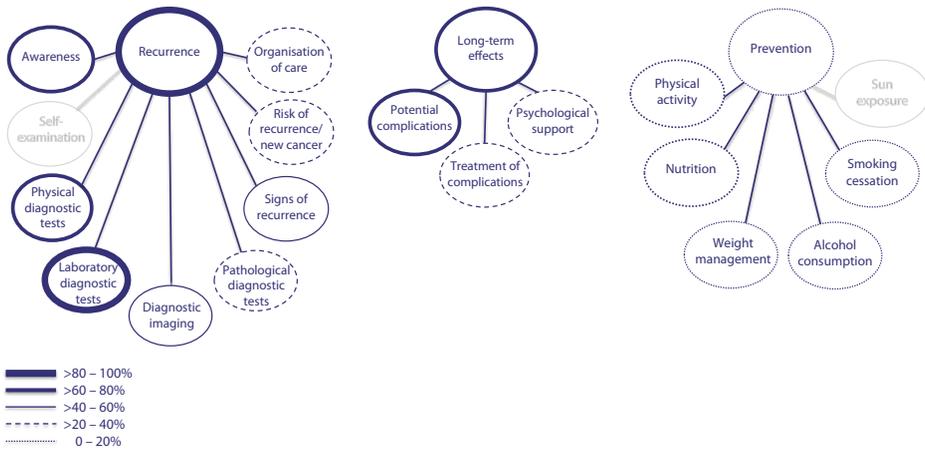
| After-care category | Topics dealt with |
|---------------------------|-----------------------------------|
| Recurrence detection (15) | Physical diagnostic tests (15) |
| | Diagnostic imaging (11) |
| | Awareness (12) |
| | Laboratory diagnostic tests (6) |
| | Risk of recurrence/new cancer (5) |
| | Organization of care (6) |
| | Signs of recurrence (11) |
| | Self-examination (13) |
| Long-term effects (8) | Potential complications (4) |
| | Treatment of complications (2) |
| | Psychological support (7) |
| Recurrence prevention (6) | Sun exposure (6) |

Note: Total number of guidelines on melanoma: 15.

Prostate cancer

Recurrence detection was discussed in all guidelines (Fig. 6.5 and Table 6.6). Most attention was paid to the value of testing for PSA, followed by digital rectal examination and awareness; other topics were less well covered. More than half of the guidelines (11 of 18) discussed long-term effects of prostate cancer, where 11 guidelines mentioned at least one potential complication. Distinction was made between urinary, sexual, bowel and other complications; urinary incontinence and erectile dysfunction were most often mentioned.

Fig. 6.5 Overview of categories and topics on after-care for prostate cancer derived from 18 guidelines



Note: Topics shown in grey were not discussed in the guidelines.

Table 6.6 Number of guidelines for prostate cancer by after-care category and number of topics dealt with per category

| After-care category | Topics dealt with |
|--------------------------------|-----------------------------------|
| Recurrence detection (18) | Physical diagnostic tests (14) |
| | Diagnostic imaging (8) |
| | Awareness (13) |
| | Laboratory diagnostic tests (18) |
| | Risk of recurrence/new cancer (5) |
| | Organization of care (7) |
| | Signs of recurrence (10) |
| | Pathological diagnostic tests (5) |
| | Long-term effects (11) |
| Treatment of complications (7) | |
| Psychological support (4) | |
| Recurrence prevention (2) | Physical activity (2) |
| | Nutrition (2) |
| | Weight management (1) |
| | Alcohol consumption (1) |
| | Smoking cessation (2) |

Note: Total number of guidelines on prostate cancer: 18.

There was not a high level of agreement across guidelines on the frequency of the two most important follow-up monitoring methods: digital rectal examination and PSA testing. The suggested frequency for digital rectal examination was either every six or every 12 months for the first three years after treatment. From the fourth year onwards, the predominant suggestion was for an annual check. There was no agreement on the frequency in the first years for PSA testing; for the second and third year guidelines leaned towards six-monthly checks. In the fourth and fifth year, there was again no agreement, while after five years it was recommended as an annual check.

Summary

All guidelines noticed that the detection of recurrence is the most important part of after-care. Although it is known which diagnostic tests are best to detect recurrence, the best frequency to perform diagnostic tests to detect cancer recurrence is not known. Compared with recurrence detection, long-term effects of cancer got less attention in the guidelines. Most breast cancer guidelines (83.3%) and more than half of the prostate cancer guidelines (61.1%) reported potential complications of the specific cancer. Guidelines on colorectal cancer, lung cancer and melanoma provided only little information on long-term effects. Prevention of cancer recurrence received by far the least attention in the guidelines and it seems that prevention recommendations are not tumour or even cancer specific. This study does not provide the best practice on after-care for GPs, but it shows the most complete practice and an overview of information on after-care (potentially relevant for GPs).

Explorative studies of after-care for cancer patients in five European countries

This section presents five case examples (selection as outlined in the Methods) describing different regional and national approaches to after-care:

- Slovenia: exploration of after-care with their GPs for cancer patients in remission;
- Norway: a standardized, comprehensive patient pathway for cancer patients treated with a non-curative intent but within a clear framework of the cancer strategy;
- the Netherlands: nesting of after-care for cancer patients with GPs and primary care settings;
- Denmark: organization of after-care for cancer patients; and
- Bulgaria: organization of after-care through a network of regional comprehensive cancer centres.

The country information collected serves to give an overview, if limited, of how cancer after-care is organized in European countries and identifies potential advantages and drawbacks of different approaches. This insight will feed into the policy recommendations on how to improve cancer after-care in the future (outlined at the end of this chapter).

The case of Slovenia: experience of GPs with cancer patient after-care

In Slovenia the transition of after-care from the hospital and specialized oncological centres to primary care is still beginning. It was decided to carry out a study that would qualitatively estimate the GPs' workload with recent cancer patients and then carry out a tentative implementation of a cancer patient pathway for after-care in GP practices/community care. So far, there had been little

information about this issue. The objectives of the study were to describe the existing practices with recent cancer patients in after-care, regardless of their current condition and disease stage; assess the relationships between GPs, other PCPs, social services and families in managing patients with cancer; and provide inputs for a better structuring of the cancer patient pathway in after-care and testing this in a certain number of GP practices.

Survey findings on GPs and GP practice characteristics

Questionnaires were completed in May and June 2015 by 32 GPs (12.8 % response rate): 27 responding GPs were female (84.4%) and the average age of responding GPs was 51.5 years (standard deviation (SD), 7.8). Data on 160 cancer patients and their treatment were collected via their GPs. More than half (18; 56.3%) of the GP offices were located in a rural area and four (12.5%) were located in nursing homes. The majority of collaborating physicians (23; 71.9%) were employed in a public primary health centre. The community care centre was on the same location as the GPs' office in two thirds of the cases (21; 65.6%).

A single GP had an average of 8501.8 (SD, 3912.5) patient contacts in year 2014, of which 55.6 (SD, 51.5) were house calls. The average number of patients per GP was 1687.8 (SD, 676.2). From those, 99.1 (SD, 95.7) were cancer patients (with active cancer or disease in remission). On average, 10.5 cancer patients (SD, 10.0) had contacts with their GP in 2014. From all the patients assigned to a single physician, 4.9% (SD, 4.4%) were cancer patients. During 2014, an average of 1.3 (SD, 1.6) cancer patients moved to nursing homes and 6.0 (SD, 5.7) died (all causes of death). Within a period of five working days, GPs had an average of 215.0 (SD, 75.2) patient contacts, from which 13.4 (SD, 11.0) were cancer patients.

Survey findings on cancer patient characteristics and GP satisfaction with hospital and community level care provision

More than half (58.8%) of the cancer patients included in the study were female and their average age was 63.4 years (SD, 14.9). The majority of patients (87.6%) were diagnosed with cancer after 2005. For patients included in the study, time to diagnosis was an average of 5.7 weeks (SD, 4.8). The most common diagnosis was malignant neoplasm of breast, affecting nearly a quarter of the cancer patients in the study (23.4%). Among the common diagnoses were malignant neoplasms of digestive organs (22.1%), malignant neoplasms of male genital organs (9.7%), malignant neoplasms of female genital organs (8.4%) and melanoma and other malignant neoplasms of skin (8.4%). Patients contacted their GP on average 10 times (SD, 9.6) in the year before the study. The majority of visits (6.2; SD, 6.6) were of administrative nature and consisted of issues such as issuing prescriptions, referrals and medical device ordinances. Less frequently, the purpose of the visits was for coordination of health care services (2.0; SD, 3.6), consultation with relatives (1.9; SD, 6.0) and psychosocial support (1.6; SD, 3.0). Coordination of social services, help with activities of daily living, palliative care and home care were seldom topics of GP visits. Disability evaluation was not undertaken frequently because the majority of the patients were no longer in active employment.

GPs were mostly satisfied (5.6 to 4.1 on a 7-point Likert scale) with patient treatment at primary and secondary care levels, existing guidelines, diagnostics possibilities, accessibility of services at the secondary care level, accessibility of pharmacological pain management and with information transfer from specialists to GP. They were somewhat dissatisfied (from 3.1 to 2.1) with medical on-call services, inclusion of family members in treatment process and with communication with specialists involved in cancer patient treatment. They were mostly dissatisfied with palliative care, willingness of other services to be involved in cancer patient treatment, accessibility of non-

pharmacological management of pain and other symptoms, organized home care and with community care services. GPs were most dissatisfied (from 1.9 to 0.4) with availability, involvement and coordination of community and social care services. However, patients seldom used these services.

Interview results

Findings from the interviews in May and June 2015 showed that physicians experience high levels of stress particularly in the early phases of cancer patient care – from time suspicion of cancer is established to time of cancer therapy initiation. In order to shorten the time before the patient with a suspicion of cancer receives diagnostic tests, GPs have to coordinate health care services. Physicians reported lack of “fast track” for suspected cancer patients, particularly in cases based on an agreement between GP and specialist. They would also value a possibility of consultation with a specialist in cases of suspicion of cancer where future management is unclear. Patients rarely meet their GP while being treated at the Institute of Oncology, which scored high in satisfaction with the treatment delivered as perceived by the GPs. While cancer patients are treated in ambulatory settings, more contacts are needed with their family members than with the patients themselves. GPs emphasized the importance of cooperation with different health care service (community care, patient transport services) during the ambulatory cancer treatment phase. GPs did not report special needs or problems during the surveillance phase of cancer care. However, they did report that there should be more emphasis on full rehabilitation of the patient, including psychosocial support. Furthermore, the interviewed physicians reported that patients need more psychological support during the after-care period. Easier access/referral to psychotherapy would benefit patients, particularly in reducing fear of cancer recurrence, according to the GPs. Respondents reported that they had struggled with palliative care of patients in the past because of lack of knowledge but the palliative care area had improved vastly in recent years. They reported having numerous palliative care courses and a specialist of palliative care available for consultation. The latter is an exception occurring in the region of Slovenia from which the interviewed physicians originate (Upper Carniola).

Development and testing recommendations

An observational retrospective study included 13 out of 32 GPs (40.6% response rate), who had already participated in the first round of the study. Data on 63 cancer patients and their treatments were collected and evaluated. Activities, most frequently performed (over 70%) included general and psychological support as well as good communication skills and care for concomitant chronic diseases. Elaboration of a written treatment and pain management plan, coordination with other community services and psychosocial rehabilitation plan were less frequent activities (under 15%). In general, there was less need for assessment of occupational disability (in 23% of patients), because most patients were already retired. Among those of working age, more than half were involved in activities related to occupational assessment and rehabilitation. GPs evaluated good practice recommendations as a useful, although sometimes too general, tool in cancer after-care; however they emphasized time shortages in comprehensive after-care. Suggestions were raised that nurses could also take part in cancer after-care.

In summary, GPs in Slovenia have an increasingly important role in the after-care of surviving cancer patients with the majority of contacts occurring for administrative reasons. However, GPs experience high burden of stress during the initial phases of a patient’s disease as well as later during after-care. Cancer patient pathway (i.e. good practice recommendations) was recognized as valuable tool for systematic approach to patients with cancer during after-care.

The Norwegian experience: the development of an integrated care pathway (the Orkdal model)

Norway decided in 2013 to strengthen the coordination of care at the regional level and introduce integrated care pathways (ICP) as a method to implement this integration into clinical practice; ICPs are structured multidisciplinary care plans that can facilitate a process by which palliative care and oncology can be integrated in a given setting. ICPs may provide a process plan, provide a time frame, describe the type of expertise needed at any step in the process and describe the resources needed during the trajectory (13,14). A recent Cochrane review concluded that ICPs reduce hospital complexity and improve documentation without having any negative impact on length of stay or hospital cost (15).

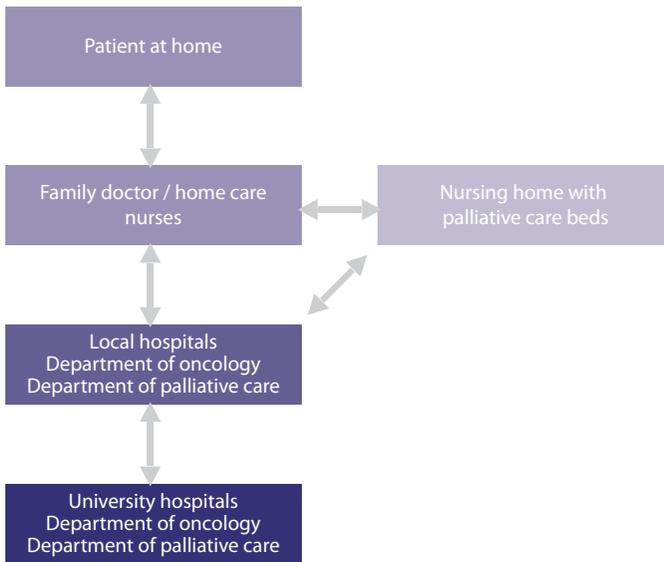
The ICP

The main component of the Orkdal model is an ICP that facilitates evidence-based practice, improves coordination of care in all phases of the disease trajectory, and integrates oncology and palliative care. The care pathway is to be applied regardless of cancer diagnosis, focusing on function, needs and symptoms, and it covers health care services in home care, nursing homes and specialist care. Symptom assessment and optimal symptom management, definition of responsibilities, optimal communication and access to cancer care services whenever needed constitute the core of the pathway. Overall, the development and use of the ICPs contributes to ensure:

- **quality** of palliative care offered (equal quality of care regardless of level);
- **responsibility** in that there is a clear definition of which health care professional is responsible for the patient at different points in time (defining the right level of care);
- **flexibility** as the patient's needs vary during the disease trajectory and may often be difficult to predict; and
- **availability** of health care services 24 hours a day/seven days a week in order to ensure safety and quality for patients and carers.

The Norwegian model for comprehensive cancer care is the basis of the ICP where GPs (with a gate-keeping role) and home-care nurses are responsible for the visiting, treating and caring of the patient at home and in community care settings (16). Specialists are available for the GPs for supervision. Patients' needs are considered in a step-up model: the first option considered is the local nursing home with specialized oncology/palliative care, then local hospital care and finally, for highly selected patients, university hospital care (Fig. 6.6). Necessary templates, checklists, assessment tools, contact information and relevant guidelines are included in the ICP. Electronic assessment of patient-reported outcomes is partially applied in the project.

Fig. 6.6 Norwegian comprehensive cancer care



Educational programme

To implement the ICP, an educational programme in oncology and palliative care is offered to the providers, mainly to physicians, nurses, and nurse assistants. Participants are encouraged to teach colleagues at their respective place of work. Resource cancer nurses organized in a network have extra responsibility for teaching and for implementing the model locally. Project positions for GPs and community cancer nurses have been offered at the outpatient clinics to achieve specialist competence in community care. A master’s programme in pain and palliative care has been established at the Norwegian University of Science and Technology, Trondheim.

Information for citizens

Through the project, patients, carers and the public are offered information regarding chemo- and radiotherapy, symptom diagnosis and treatment, available expertise, volunteers, educational courses for patients and carers, and who to contact. The information is given as written materials, electronically and at public meetings. Educating patients in systematically reporting of needs and symptoms and about available oncology and palliative services is important to achieve high-quality care where the patient is actively taking part in treatment decisions and planning of their care.

Advantages of the integrated cancer care pathway

The care pathway increases the quality of care (17). Some of the experienced advantages (17–20) that have been identified so far in the participating municipalities are:

- systematic symptom assessment and evaluation of different treatments according to the patient reported symptoms, function and needs;
- higher degree of collaboration and better coordination of services, including fewer unnecessary consultations and better planning of what services the individual patient and family may need;
- clarification of treatment intention and a clear treatment plan;

- fewer unnecessary potential toxic anticancer treatments;
- medication lists updated more often;;
- improved communication between health care providers across levels of care, including better written reports that are available at the time of change of place of care;
- improved communication between health care providers and the patient;
- improved communication between health care providers and the carers; and
- support from management in the specialist and community care needed to succeed with implementation.

Advantages of the educational programme

After participating at courses focusing on integrated cancer care, the GPs are more aware of the cancer patients and their potential needs for closer follow-up in all phases of their disease (i.e. after being cured, living with metastatic disease and at the end of life). PCPs in community care are more aware of further available expertise locally and in specialist care. Because they have support from specialist care, they are to a larger extent able to take more responsibility locally and for patients with complex cancer. GPs and cancer nurses educated thorough project positions at the outpatient clinic now working locally and are providing specialist competence at community care level, which is made possible through more health care providers locally having more knowledge in oncology and palliative care. Consequently, oncologists are able to spend their time specifically on oncological treatment and the most complex disorders. Furthermore, fewer hospitalizations may be needed and potential toxic anticancer treatment might be stopped earlier or largely not started when appropriate.

Advantages of information for citizens

Better-informed patients and families make in many cases better treatment decisions and improve communication. The patients may feel more confident and that the disease trajectory is more predictable. Patients may report symptoms more reliable and may be better educated to ask for available services such as appropriate treatment for pain and nausea or advice from a social worker.

In summary, the ICP, educational programmes for PCPs and information delivered to citizens increase quality of care, improve communication across levels of care and with patients and contribute to better treatment decisions.

The Netherlands: the role of primary care in after-care for cancer

In 2013 and 2014, NIVEL published a series of papers based on studies that analysed the characteristics of cancer patients in primary care, the resulting workload and the consequent impact on the development of these services at the primary care level in the Netherlands. Key findings of these studies are summarized below.

Primary care for cancer survivors

While Dutch GPs have no formal role in follow-up visits in the first five years after diagnosis of cancer, they are involved in care for cancer survivors. As many cancer patients are older and have chronic diseases in addition to cancer, they visit their GP for various other health problems. At the end of the follow-up visits with the medical specialist, GPs take over the care for patients.

The number of cancer survivors per GP practice is considerable. In an average practice of 2350 listed patients (1.0 full-time equivalent GP), about 70 patients had been diagnosed with cancer less than nine years previously (21). Cancer survivors have more GP contacts than those of the same age and sex without cancer (Table 6.7). In the first years after diagnosis, cancer survivors have a higher number of office visits and telephone consultations and the GP more often pays home visits. Cancer survivors also have a higher number of medication prescriptions and referrals to secondary care (22–25). Patients who are over 60 years of age and have been treated with breast-conserving surgery may be referred to their GP for yearly follow-up visits, with a mammography every two years. After the initial treatment for prostate cancer, clinical examination and PSA measurement are recommended after six weeks, at three, six and 12 months, and then every six months for the three years after diagnosis and annually from five to 10 years. After five years, patients with stable low PSA levels may be referred to the GP.

Table 6.7 Mean number of GP contacts per year in Dutch cancer survivors compared with age- and sex-matched controls without cancer from the same GP practice

| | Breast cancer | | Prostate cancer | | Colorectal cancer | | All types of cancer ^c | |
|-----------------|-----------------------|-----------------------|-----------------|---------|-------------------|---------|----------------------------------|---------|
| | Survivor | Control | Survivor | Control | Survivor | Control | Survivor | Control |
| Practice visits | 3.3–4.0 ^{ab} | 2.9–3.2 ^{ab} | 3.6 | 2.9 | 3.5 | 3.0 | 3.5 | 2.7 |
| Telephone | 0.8 | 0.4 | 1.2 | 0.7 | 1.2 | 0.8 | – | – |
| Home visit | 1.2 | 0.9 | 1.1 | 0.7 | 1.2 | 1.0 | 1.6 | 0.4 |
| Total | 5.3–6.0 | 4.2–4.5 | 5.9 | 4.3 | 5.9 | 4.8 | | |

^aBreast, prostate and colorectal cancer 2–5 years after diagnosis (22); ^bbreast cancer a median of 1 year after diagnosis (25); ^call cancer types at less than 6 months after diagnosis (23).

The number of GP contacts varies widely between patients. As expected, older patients and those with a chronic disease have the highest number of GP contacts. Cancer survivors aged 50 years without a chronic disease have, on average, three to four GP contacts per year, while those aged 80 with a chronic disease have, on average, eight to nine contacts per year. The increase in the number of GP contacts with age and with the number of chronic diseases is similar in cancer survivors and controls without cancer (26).

Health problems for which cancer survivors visit their GP

The health problems for which cancer survivors visit their GP differ by cancer type. Breast cancer survivors visit their GP more often for acute symptoms, such as back or abdominal pain, in the period of two to five years after diagnosis. They also visit the GP more frequently for common infections, such as cystitis or respiratory infections (27). The GP also frequently take over the management of hormone or aromatase inhibitor use, which was originally initiated by a specialist. Although breast cancer survivors do not visit their GP more often for psychosocial problems, GPs more often prescribe psychomedication to these patients.

In the two to five years after diagnosis, prostate cancer survivors visit their GP more often for general symptoms, such as fatigue, constipation and back pain, but surprisingly not for urinary incontinence or erectile dysfunction. Colorectal cancer survivors visit their GP more often for infections, such as skin or urinary infections, but also because of anaemia, abdominal pain and side-effects of treatment.

In conclusion, cancer survivors visit their GP more often for common acute symptoms, such as fatigue, pain and common infections. This may be related to late effects of cancer treatment. Both fatigue and pain often develop during treatment and may persist thereafter. Infections may occur because of a weakened immune system. Alternatively, cancer survivors may be more prone to visit their GP for these relatively common symptoms because of increased health concerns. The number of GP contacts related to chronic diseases and psychosocial problems is slightly higher in cancer survivors but is not a major cause for the increase in health care use.

Estimated increase of GP contacts in the Netherlands in the future

Following the increasing incidence of cancer and improving survival for cancer, it is expected that the number of patients living with cancer in the Netherlands will increase from 419 000 in 2009 to 666 000 in 2020 (28). As these patients frequently contact their GP, this will also lead to an increase in GP contacts. Researchers from NIVEL have estimated the rise in contacts will follow two scenarios. The first scenario takes into account the estimated increase in the number of cancer survivors. The second scenario also takes into account the current debate to increase the role of the GP for after-care. GPs are already involved in care for these patients; they often see these patients for chronic diseases besides cancer and their practices are usually near to their patients' residences. It is, therefore, suggested that part of after-care should be transferred from the specialist to the GP. In the second scenario it is assumed that this will lead to two additional GP contacts per year. In Table 6.8, the estimated number of contacts in the Netherlands and the number of contacts for a standard GP practice (with 2350 listed patients) is given (29). It is estimated that in 2020 a standard GP practice will have 850–1100 contacts with cancer survivors, about 20 contacts per week. This is an increase of 70–120% compared with 2010.

Table 6.8 Number of contacts per year that GPs have with cancer survivors in the Netherlands

| | 2010 | 2020: based on increase in patients | 2020: based on increase in patients + 2 contacts per year from specialist care |
|------------------------------------|-----------|--|---|
| Total | 3 600 000 | 6 000 000 | 7 600 000 |
| Per norm practice (2 350 patients) | 500 | 850 | 1 100 |

Source: Signaleringscommissie KWF (29).

In summary, GPs in the Netherlands have an important role in the after-care of surviving cancer patients, as demonstrated by the higher number of contacts compared with patients without cancer. Cancer patients visit their GP for common health problems. With the increasing number of surviving cancer patients, GPs might be also involved in the future in oncological after-care for surviving cancer patients.

Denmark: organization of cancer after-care in primary care settings

In Denmark, a reform of after-care is in progress, following reports of waste caused by unnecessary oncological hospital-based follow-up of cancer survivors. This reform also comes out of need for rational use of the resources in cancer care before an expected increase in cancer patients caused by the ageing population. The main characteristics of this ongoing reform process are described below.

The working process and timeline

Following discussions in 2010–2012 on the need for a reform in cancer after-care, the decision to reform was taken in 2012. In 2013, a specified working plan was agreed where the Danish Health Authority would chair a series of working groups that would describe the follow-up for each main type of cancer. These plans on follow-up care would be worked out in collaboration with relevant administrative and clinical stakeholders (the multidisciplinary national cancer groups) including representatives from general practice. The plans would be amendment to the already created national fast track system for diagnosis and treatment of each cancer. The implementation of the reform was scheduled for the end of 2015 and the beginning of 2016.

The content of each plan

Each plan would follow a standardized scheme and it was printed (some 30–40 pages) and put on the web by the National Board of Health (30). The following items would be addressed in each plan:

- an individual needs assessment for each patient and clear agreement with each patient about the follow-up plan following completed primary treatment;
- description of symptoms and signs of recurrence and strategy to identify recurrence;
- rehabilitation and palliation assessment and planning;
- psychosocial, spiritual and existential considerations including ways to empower patients and involve them; and
- the evidence base for the recommendations in each guideline would be identified.

Implementation in 2016

Fourteen groups have developed 19 new guidelines with eight in the implementation phase. The five regions, which are also the hospital owners, have a strong focus on the implementation process, which they try to follow in a nationally agreed form. There are still not confirmed agreements on information technology monitoring and monitoring of the process. Each plan has a description of some sort of a stratified approach with tasks for specialists, nurses in hospital and for GPs.

The implementation will follow three steps.

- 1 Breast, gynaecological cancers, colorectal cancer and prostate cancer (under implementation)
- 2 Head and neck, brain, sarcoma, melanoma
- 3 The rest of cancers.

There is still no agreed work plan and payment plan for GPs involvement, but it is anticipated that they only will be involved to a larger degree in prostate cancer and for the other cancers; their role will probably be patient attendance on an ad hoc need-based way. There is no specific agreement for how to establish an integrated trajectory as patients will be (for now) regarded as oncological patients and not transferred/referred to primary care. There is no specific agreement on how GPs may access specialized services, including fast and direct investigation methods and help from consultants.

Bulgaria: organization of cancer after-care in regional cancer centres

Follow-up of patients within the Bulgarian health care system is part of the development and implementation of activities and services within the framework of a more comprehensive

approach to cancer concentrated within specialists' expertise in comprehensive cancer centres, not within primary care. In this setting, how do comprehensive cancer centres deliver after-care and are patients and professionals satisfied with this arrangement?

Seven comprehensive cancer centres were approached and four of them returned completed questionnaires: Sofia, Veliko Tynovo, Burgas and Stara Zagora (detailed information from the questionnaires is provided as supplemental information at www.cancercontrol.eu). The results indicate the small number of doctors working within a comprehensive cancer centre in comparison with the very high numbers of patients and examinations conducted. Despite the fact that consultation with relatives is part of a clinician's practice, provision of psychosocial care within the centres is usually lacking. In relation to coordination of health services and social services, comprehensive cancer centres are not reported to have such responsibilities.

Comparison of data on doctors' and patients' experiences indicates several significant differences. There is a gap between the satisfaction expressed by doctors and that by patients. When asked about their experience of treatment of oncological patients at the secondary level, patients were largely satisfied, while the doctors were dissatisfied. The same discrepancy emerged in terms of participation of other services in the treatment of patients. Organized home care (when needed) was considered unsatisfactory by the doctors, while for patients it was satisfactory. Doctors felt that the involvement of family members in the care of the patient and the role of the community social care services were areas that would need further improvement (overall reported as being neither satisfied, nor dissatisfied) whereas these two topics were reported as being satisfactory in terms of patients' experience.

When comparing results from doctors and cancer patients, it was established that there are some clear similarities, such as satisfaction on existing guidelines, availability of pharmacological substances for pain relief, communication of clinical specialists in after-care and replacement in case of absence. The specific characteristics of the health care system and the role of GPs in oncological treatment and after-care were evident in the level of dissatisfaction about issues of treatment of oncological patients at the primary level experienced both by the doctors and by the patients.

The qualitative interviews showed that GPs consider the provided after-care for cancer patients as being inadequate and the patients' needs unmet (in terms of psychological and social support and the feeling of isolation in the process of treatment). In terms of patients' experience, there is a strong assumption about feelings of dissatisfaction as usually the patient has to wait for treatment and after-care because of the large number of cancer patients and the limited number of medical specialists; consequently, this situation causes more distress. Moreover, it is a huge obstacle for the patients to remain in employment and to keep up the "unnecessary" bureaucratic procedure related to it.

The prospect of engaging the GPs within the process of after-care is not considered a possibility. In reality, doctors' expectations of primary care are regular monitoring and home care of cancer patients, assistance in diagnosis and better electronic communication. Doctors feel that within the primary levels, GPs have to provide services such as examinations, psychosocial care, home care, help with the activities of daily living, prescriptions, planning of care and working disability assessment. Other experts and organization should assist in issues of palliative care, coordination of health and social services and family consultations.

Discussion

The changing developments in cancer diagnosis result in a growing number of people who survive cancer (31). As a result, the role of after-care is becoming increasingly important, but also challenging from the point of view of the volume of this care. Oncologists in hospitals often provide cancer after-care (32) but are facing challenges, such as limited hospital capacity and increasing patient numbers. At the health policy level, there are pressures to substitute care by replacing specialist-led care by GP-led care. Consequently, there are increasing calls for greater involvement of GPs in the after-care of cancer survivors. To give PCPs a greater role, however, raises the question of what information and resources GPs can draw on to provide after-care.

This chapter give an overview of evidence- and opinion-based recommendations on after-care for cancer survivors that are (potentially) relevant for GPs. Guidelines on the five most common tumour types were studied and information on three categories – recurrence detection, long-term effects and recurrence prevention – was provided for all tumour types. The inventory highlights that there is not always sufficient evidence on the best way to provide after-care nor conclusive proof about the optimal frequency of after-care diagnostic testing. Furthermore, most information provided by guidelines was not evidence based, indicating a need for research on after-care for cancer survivors. There is a clear need to improve guidelines with respect to the different providers who are increasingly involved in after-care as well as training of GPs and other PCPs, because they will face rising patient needs that will realistically be covered only by the PCPs.

The chapter also presents an overview of national and regional practices on how cancer after-care is organized in Bulgaria, Denmark, the Netherlands, Norway and Slovenia. Four of these countries have a GP-gate-keeping system and a strong role of community care, including in the cancer after-care process. Only in Bulgaria does after-care remain the task of cancer hospitals.

In Slovenia, GPs coordinate health care services during the early diagnostic period of cancer patient care. Later, patients rarely meet their GP while being treated at the specialist centres. In after-care, the majority of clinical visits are of administrative nature, but they also include coordination of health care services, consultation with relatives and psychosocial support. GPs emphasized the importance of cooperation with different health care services during all phases of cancer care.

Norwegian experience is based on ICPs that facilitates evidence-based practice, coordination of care and integration between oncology and palliative care. Use of ICPs contributes to quality of care, clear definition of responsibilities, a flexible approach to patient's needs and availability of services. The care pathway involves home care, nursing homes and specialist care.

Dutch GPs are involved in the care for cancer survivors not earlier than five years after diagnosis of cancer. They provide consultations for common problems or late effects of cancer treatment. Cancer survivors have more GP contacts than patients without cancer.

In Denmark, a reform of after-care is in progress. It is expected that plans on follow-up care will be prepared for each main type of cancer. Involvement of GPs in planned after-care is not yet agreed and GPs will probably see patients on an ad hoc needs-based way.

After-care in Bulgaria is provided in comprehensive cancer centres. Coordination with home and social care services is often poor, although patients feel satisfied with it. Stronger involvement of GPs is not considered as a relevant option.

The five different country cases have only few elements of cancer after-care in common. Countries with GP-based system implemented comprehensive (e.g. Norway, Denmark) or fragmented (e.g. Slovenia) mechanisms of coordination across levels of care. These mechanisms range from a full integration model (e.g. Orkdal model, Danish reform), where care pathways link providers, professionals and services around patient needs, to a fragmented approach, where coordination of care is a matter of GP's core competencies rather than systematic (e.g. Slovenia). Dutch experience fits between these two. Bulgaria, as an example of a country with centralized cancer care, struggles with scarce resources and after-care is not at the top of the agenda.

All these challenges are important, as is the need for sharing all patient information and developing joint files. Seamless care requires proper access to all data and information through linkages between clinical data and outpatient and primary care data and registries. Such an approach would be helpful in providing continuity and comprehensive information for everyone involved in continued cancer care.

Conclusions and recommendations

Europe presents a wide variety of approaches in the organization of cancer after-care. In many cases, hospitals and oncological services at the in- and outpatient level continue to provide a large part of after-care. Under such circumstances, the role of PCPs remains supportive to the process and important in terms of securing all the other services and for integration with other sectors to cover issues such as patients' employment and material and psychological needs. PCPs also need to ensure proper care for other chronic conditions that these patients may have at the time of the cancer diagnosis or that may be diagnosed later. Such patients will inevitably become frequent users of community care services. Nevertheless, as cancer incidence continues to increase, and modern oncological care becomes ever more specialized, focused and intense, the question arises as to how high-quality after-care and long-term supervision for stable patients in remission can be organized while taking their diverse needs and expectations, as well as cost-effectiveness, into account. Cancer is a specific noncommunicable disease that can be successfully treated and cured, unlike most of the other noncommunicable diseases. This means that overcoming cancer is a reality and leads (former) patients, their carers and the professional staff treating and monitoring them into new challenges related to survivorship.

In this exploration of cancer after-care services and the typology of providers, the experiences of five different countries were examined, some of which were going through a transformation of their existing practices. The selection of countries depended on the willingness of their respective ministries of health and the representative institutions to participate, and not on any predefined set of criteria. Nevertheless, we believe that this insight into after-care practices provides valuable insight into the current state of after-care as well as for the potential for improvements. Our objective was to propose a blueprint for a cancer patient pathway in after-care. After the survey on after-care in EU Member States, and also based on some previous experience in the participating countries, it became clear that such a pathway would not be feasible. Health care systems, the modalities and mechanisms of their financing and the traditions across countries vary importantly and do not allow for a higher level of uniformity. In spite of this conclusion, we believe that the contributions from the participating countries are important for the following reasons.

- We have been able to obtain clear and comprehensive data on the existence and applicability of guidelines for after-care and discovered both discrepancies in information and guidance as well as in the provision of after-care.
- We could identify the need to dedicate more time to the development of prevention guidelines for cancer survivors, focusing particularly on secondary and tertiary prevention, while not forgetting about health determinants.
- We have explored five countries with different approaches to after-care and which are at different stages in the transition from hospital to primary care:
 - Bulgaria, where provision of after-care is limited to cancer centres, which is a model that might work when both patient expectations and PCP's wishes are supporting such a choice;
 - the Netherlands, where important information on long-term challenges for PCP posed by cancer survivors are highlighted, including increased workloads, spousal and carer burden and additional training and knowledge needs;
 - Denmark, where a transition process, ongoing in 2016, is intended to integrate patient after-care among specialists, nurses in hospitals and GPs;
 - Norway, where a country with geographical challenges is trying to find ways to bring survivorship support, after-care and palliative care closer to where patients live (without losing the quality and efficiency of these types of care); and
 - Slovenia, where GP practices appear to be overwhelmed with the challenges presented by increasing numbers of with cancer patients but are developing elements of a future care pathway for after-care for cancer patients.

Recommendations

This overview gives policy-makers/guideline developers the opportunity to discuss different after-care topic actions, tests and awareness, sometimes supplied with frequencies that could be included into their own guidelines on after-care for a specific tumour type. It also shows that preparing a comprehensive/integrated patient pathway is important for several reasons.

- seamless care is needed and expected; the care needs to be continued across the formal institutional boundaries;
- patient information is crucial; patients need to be fully and comprehensively informed about the processes related to their continued care; and
- guideline implementation is needed (when and where these are in place) to structure care around the evidence-based milestones (patient pathway represents a common tool for guideline implementation).

For the future development of cancer after-care we recommend the following.

- 1 Manage cancer as a continuous process where patients seamlessly 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. It is important to:

- 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 PCPs; 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 Organize the education and training for PCPs in order to strengthen their capacity to cope with the increasing population of cancer patients in after-care.
 - 3 Develop guidelines and guidance, at least for each of the most frequent cancers, on what to include and on what not to include in the long-term monitoring of patients (system specific, differences in access to some tests and diagnostics). This should 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, defining and elaborating for the patients' after-care in terms of the responsibilities of GPs (in case they are willing to perform this role);
 - b/ long-term effects of cancer, where there should be more information on the potential complications of individual types and locations of cancer and how these should be prevented and treated; furthermore, more knowledge and recommendations on psychological support for cancer survivors are warranted; and
 - c/ recurrence prevention, where there should be more research into the value of recurrence prevention and specific recommendations for cancer survivors.
 - 4 Coordinate services between the health and other sectors for many patients not only for those who 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 productivity).

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