

Community cancer care (after-care) – policy recommendations for quality improvement

Cancer Control Joint Action



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Presentation

- Scope
- Methods
- Findings
- Recommendations

Scope

- Chapter focuses on the organisation of after-care and supportive care for patients, predominantly outside of the specialised oncological care, and for those patients who require further interactions with primary and social care because of their cancer treatment.
- Defining after care
- Outlining how after care is organized in certain European countries (Bulgaria, Denmark, the Netherlands, Norway, Slovenia)
- Indicating the need to structure and plan the care

Methods

- Survey of experts and country informants, and literature review of existing guidelines on after care for breast, colorectal, lung, melanoma and prostate cancer
- Exploration of after care organisation and services in 5 countries
 - Slovenian pilot study (survey on after care in GP, development and assessment of after care pathway / recommendations)
 - Orkdal model, Norway – (sub)regional organisational model of after care
 - Challenges and patient needs in after care in the Netherlands
 - Danish organisational reform in after care
 - Interviews with regional cancer centres in Bulgaria on after care

Findings – survey, inventory, recommendations (NIVEL)

- National experts (EU + 4 countries) were approached to identify guidelines on after care and potentially relevant for GPs
- Literature review on international guidelines
- Out of 32 countries, 12 had no tumor specific guidelines, additional 7 countries couldn't provide guidelines they allegedly have.
- 77 guidelines received, 47 deemed relevant.
- In literature / internet search 48 guidelines were identified
- Inventory included 95 guidelines from 36 countries

Findings – survey, inventory, recommendations (NIVEL)

Table 1. Number of guidelines and their focuses concerning after-care guidelines and providers

Cancer location	Number of guidelines	Countries with guidelines	Specific to after-care	Scientific reference to after-care	Guide for GPs
Breast cancer	24	19	7	17	2
Colorectal cancer	21	16	6	12	1
Lung cancer	17	11	3	9	1
Melanoma	15	13	1	12	1
Prostate cancer	18	14	4	14	1

Findings – survey, inventory, recommendations (NIVEL)

- Categorizing / summarizing into topics:
 - 2 independent researchers.
 - Disagreements resolved with involvement of 3rd researcher.
- List of (uniform) categories and topics for various tumors:
 - Categories (3): recurrence detection, long-term effects, recurrence prevention.
 - Topics (18): physical diagnostic tests, diagnostic imaging, laboratory diagnostic tests, pathological diagnostic tests, organisation of care, risk of recurrence / new cancer, signs of recurrence, self-examination, awareness, potential complications, treatment of complications, psychological support, physical activity, nutrition, weight management, alcohol consumption, smoking cessation, sun exposure.

Findings – survey, inventory, recommendations (NIVEL)

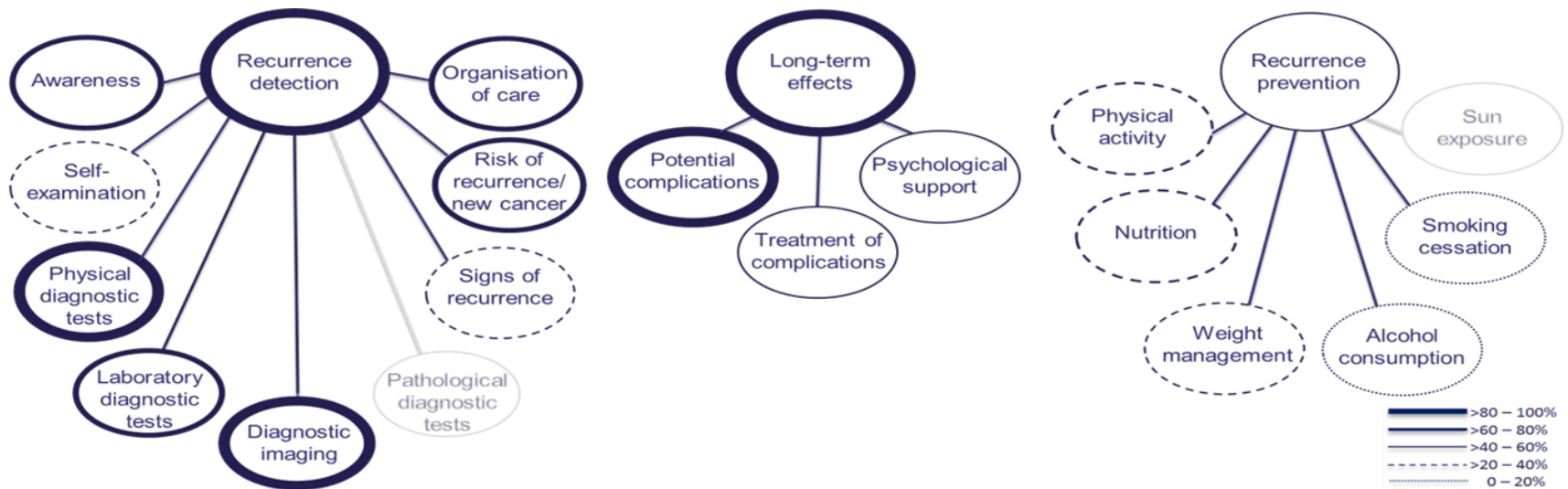


Figure 1. Overview of categories and topics on after-care for breast cancer derived from 24 guidelines Note. Topics shown in grey were not discussed in the breast cancer guidelines

Findings – survey, inventory, recommendations (NIVEL)

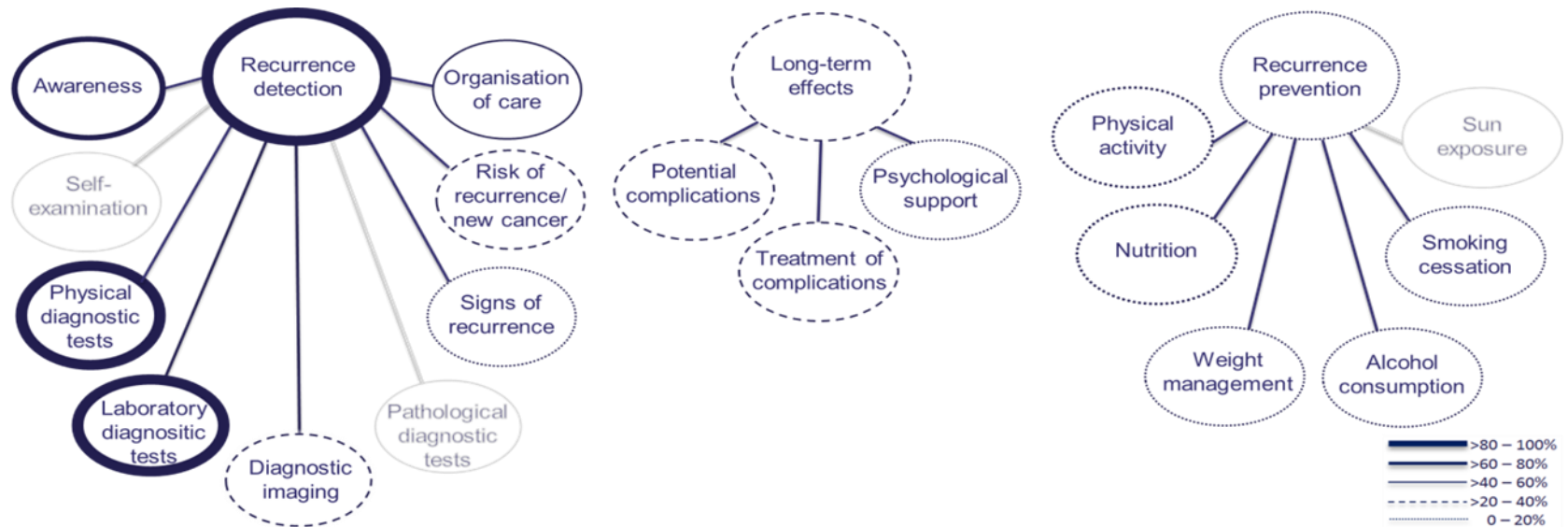


Figure 2. Overview of categories and topics on after-care for colorectal cancer derived from 20 guidelines. Note. Topics shown in grey were not discussed in the colorectal cancer guidelines.

Findings – survey, inventory, recommendations (NIVEL)

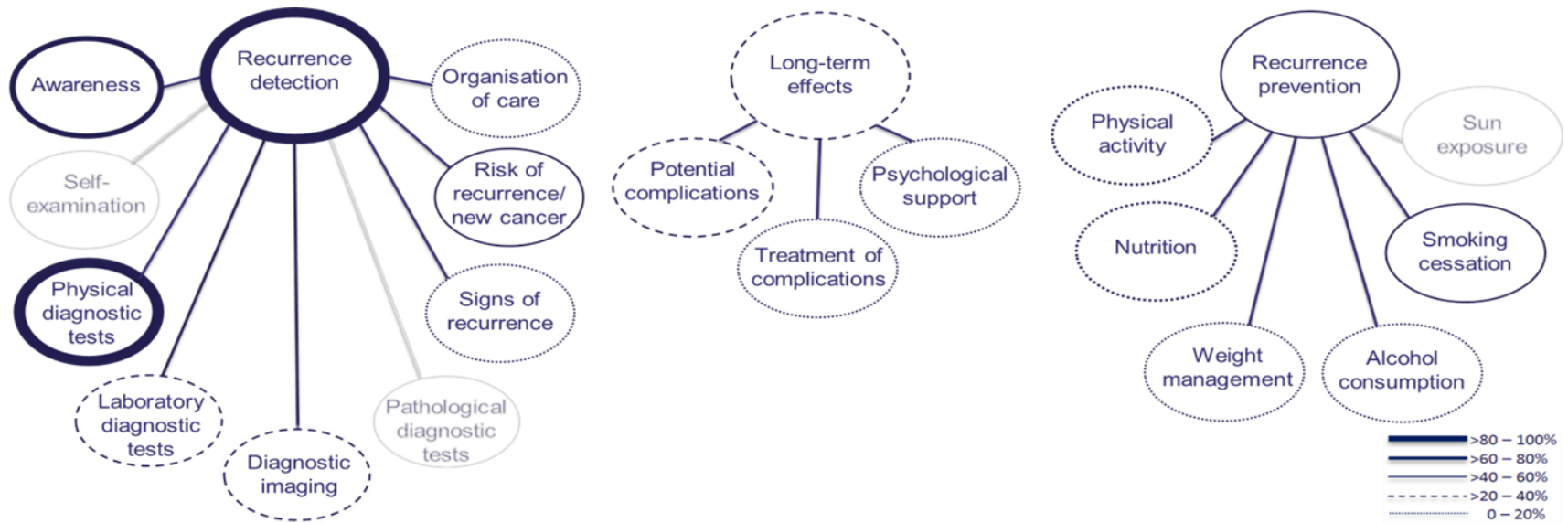


Figure 3. Overview of categories and topics on after-care for lung cancer derived from 15 guidelines. Note. Topics shown in grey were not discussed in the lung cancer guidelines.

Findings – survey, inventory, recommendations (NIVEL)

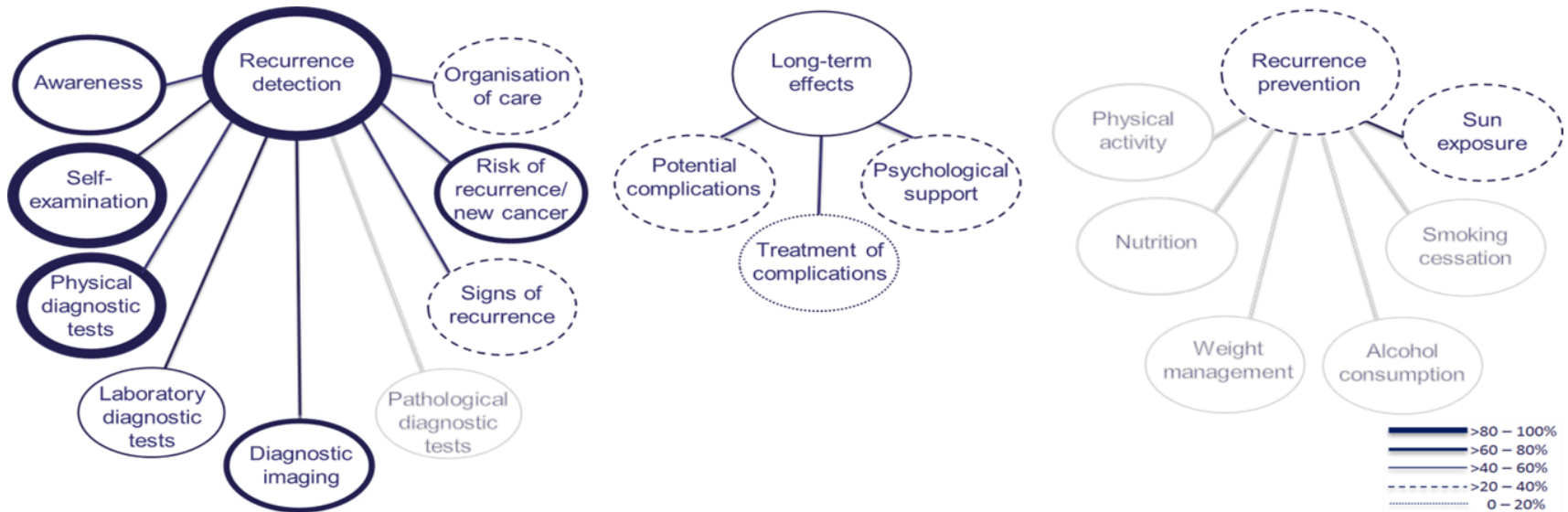


Figure 4. Overview of categories and topics on after-care for melanoma derived from 15 guidelines. Note. Topics shown in grey were not discussed in the melanoma guidelines

Findings – survey, inventory, recommendations (NIVEL)

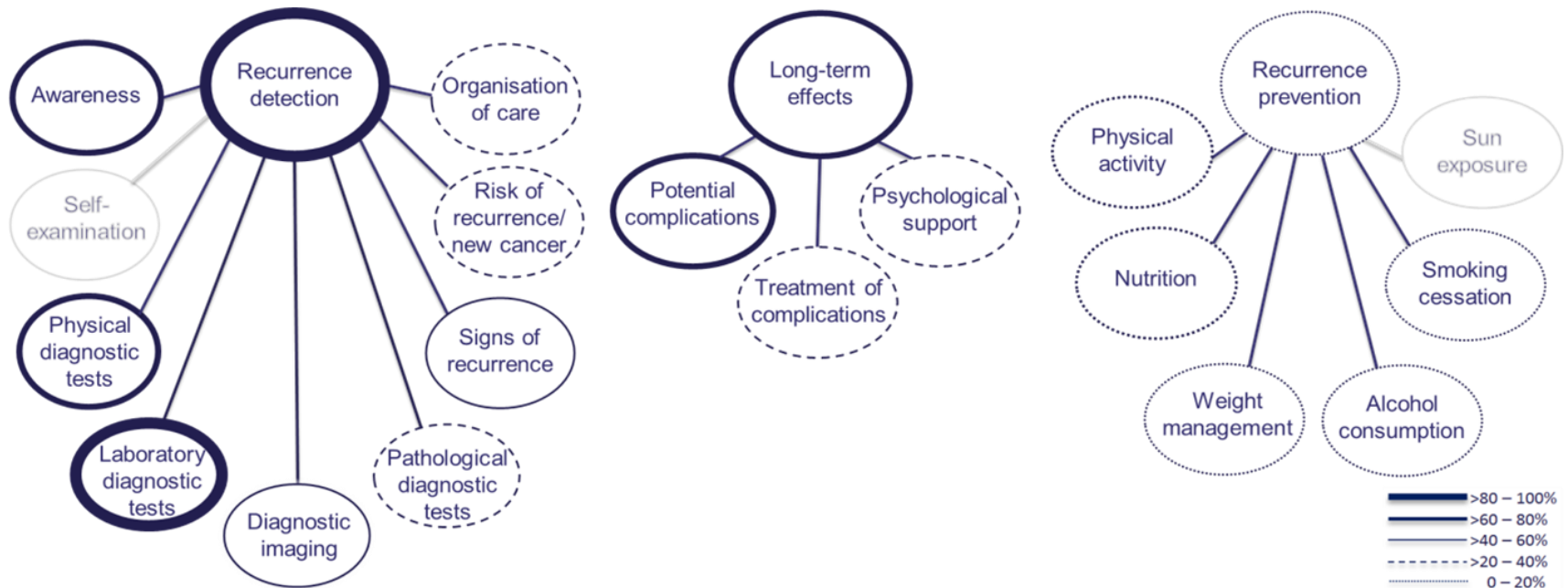


Figure 5. Overview of categories and topics on after-care for prostate cancer derived from 18 guidelines. Note. Topics shown in grey were not discussed in the prostate cancer guidelines

Findings – Slovenian pilot study (NIJZ, OZG)

- Survey on characteristics of GP practice, cancer patients (first 5 in one week) and workload, and GPs' assessment of cancer care provided on hospital and community level
- Development and testing of good practice recommendations (pathway) for after care
- 32 (out of 250) practices responded, 160 cancer patients were included
- 13 (out of 32) practices, 63 cancer patients were involved in testing the pathway

Findings – Slovenian pilot study (NIJZ, OZG)

- First 5 patients with cancer (160)
 - Women (59%), age (63,4 yrs)
 - Year of diagnosis: 2010
 - Diagnosis: 23,4% breast cancer, 13,8% colorectal cancer, 8,2% prostate cancer, 6,3% malignant melanoma, 5,7% stomach, 5,2% lung cancer, 4,3% ovarian cancer, 4,3% kidney cancer, 2,6% oropharynx
 - 10 contacts in last year: 6,2 administrative, 2 coordination of health services, 1,9 consultation with relatives, 1,6 psychosocial care; seldom: palliative care, assistance with daily living, home nursing care

Findings – Slovenian pilot study (NIJZ, OZG)

- Physicians' assessment of health (after) care (satisfaction – Lickert scale 1-7) delivered to first 5 patients with cancer
 - Secondary care (5,4)
 - Guidelines and recommendations (5,1)
 - Diagnostic opportunities (5,1)
 - Accessibility of secondary care (5,0)
 - (Timeliness of) Care for newly diagnosed cancer patients (4,9)
 - Availability of drugs for pain management (and palliation) and for other symptoms (4,8; 4,1)

Findings – Slovenian pilot study (NIJZ, OZG)

- Physicians' assessment of health (after) care (satisfaction – Lickert scale 1-7) delivered to first 5 patients with cancer
 - Communication with clinical specialists (when needed) including transfer of patient information / records (3,1)
 - Organization of home care, including community nursing (2,1; 63% weren't in need)
 - Palliative care (delivered by other professionals) (1,5; 68,6% weren't in need)

Findings – Slovenian pilot study (NIJZ, OZG), good practice recommendations

VODENJE BOLNIKOV Z RAKAVO BOLEZNIJO V DRUŽINSKI MEDICINI V OBDOBJU, KO JE SPECIFIČNO ONKOLOŠKO ZDRAVLJENJE ZAKLJUČENO

IZVAJANJE PRIMARNE ZDRAVSTVENE OSKRBE	V OSEBO USMERJENA ZDRAVSTVENA OSKRBA	ZMOŽNOST REŠEVANJA SPECIFIČNIH PROBLEMOV	CELOVITO OBLIKOVANJE MODELOV	USMERJENOST V SKUPNOST	CELOSTNI PRISTOP
<ul style="list-style-type: none"> • Načrt vodenja • Obdobjna ocena potrebnosti vključevanja drugih strokovnjakov na primarni ravni • Obdobjna ocena potrebe po vključitvi sekundarne ravni zdravstvenega varstva • Izdelava načrta zdravljenja v pisni obliki pri paliativnih bolnikih • Organizacija in izvedba sestankov razširjenega tima 	<ul style="list-style-type: none"> • Pridobivanje informacij glede družinske anamneze in obdobjna posodobitev le-te • Krepitev odnosa zdravnik/bolnik ob vsakem posvetu • Nudjenje psihološke podpore bolnikom • Uporaba primerne komunikacije in veččin sporazumevanje pri vsakem posvetu • Vključevanje družine, koder je to potrebno, po možnosti v obliki družinske konference 	<ul style="list-style-type: none"> • Aktivno iskanje podatkov iz anamneze in kliničnega pregleda, ki bi nakazovali na ponovitev bolezni • Preverjanje adherence do zdravljenja • Preverjanje morebitnih stranskih učinkov zdravil • Aktivno iskanje anksiozno-depresivnih motenj • Izdelava načrta nadzora bolečine • Racionalna uporaba preiskav ob sumu na morebitna poslabšanja stanja, sumu na recidiv/progres bolezni • Racionalno napotovanje h kliničnim specialistom ob sumu na morebitna poslabšanja stanja 	<ul style="list-style-type: none"> • Spodbujanje zdravega načina življenja ob vsakem posvetu • Izdelava seznama cepljenj • Izdelava načrta rehabilitacije in vračanja na delovno mesto • Aktivno iskanje vzroka težjega vračanja na delovno mesto • Izdelava predloga za oceno delazmožnosti • Sočasna obravnava morebitnih kroničnih bolezni • Izdelava zbirnika kroničnih bolezni in stanj • Izdelava seznama stalne terapije zdravil • Obdoben pregled zdravil, ki jih bolnik prejema • Natančno informiranje bolnika glede načinov izvajanja zdravljenja 	<ul style="list-style-type: none"> • Sodelovanje z drugimi službami v skupnosti • Sodelovanje s skupinami oz. organizacijami bolnikov 	<ul style="list-style-type: none"> • Prepoznavs kulturnega, verskega, etničnega in socialnega ozadja in vrednotenje vpliva le-tega na obravnavo bolnika • Prepoznavs bolnikovih pričakovanj, stališč in želja glede vodenja bolezni in vključitev le-teh v načrt zdravljenja



Findings – Slovenian pilot study (NIJZ, OZG)

- Piloting the recommendations / pathway
 - Frequently performed: general and psychological support, good communication skills and care for concomitant chronic diseases
 - Rarely performed: elaboration of a written treatment and pain management plan, coordination with other primary services and psychosocial rehabilitation plan
 - Less need for assessment of occupational disability

Findings – Orkdal model (standardized cancer care pathway including palliative care), NTNU

- Total integration model implemented in 2012. It provides one-stop oncologic curative and palliative treatment. Intervention consists of integrated care pathway, an educational programme, and information to the citizens.
- Evaluation of the programme is performed as a prospective controlled observational pre- post cohort study (results not yet available).
- Integrated care pathway facilitates evidence-based practice, improved coordination of care in all phases of the disease trajectory, and integration between oncology and palliative care. The care pathway is to be applied regardless of cancer diagnosis, focusing on function, needs and symptoms, and covers health care services in home care, nursing homes, and specialist care.

Findings – Orkdal model (standardized cancer care pathway including palliative care), NTNU

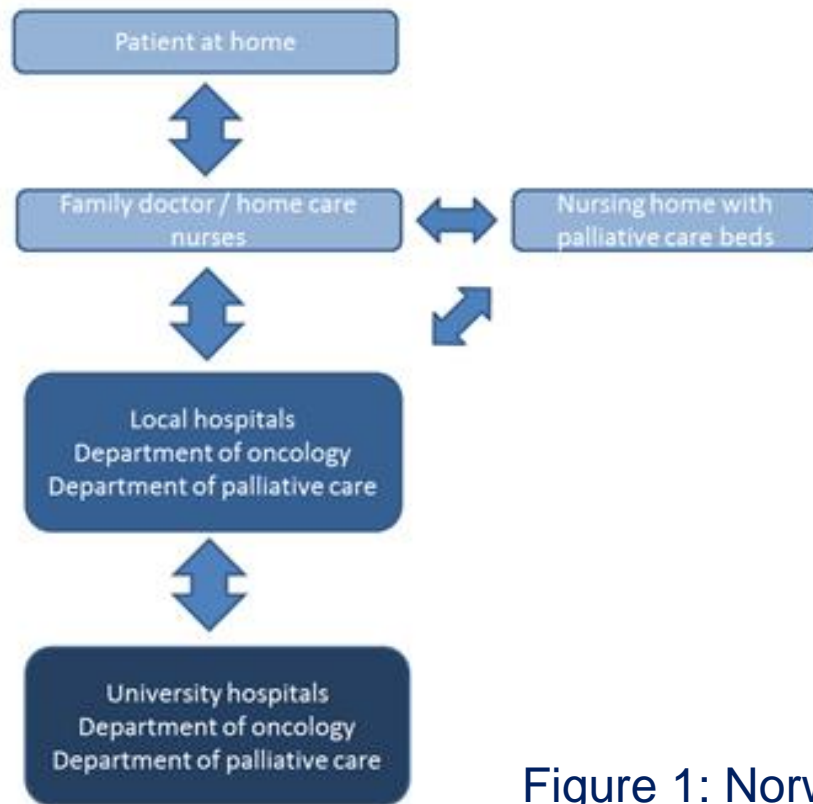


Figure 1: Norwegian comprehensive cancer care

Findings – Netherlands case, the role of primary care in after care for cancer, NIVEL

- 70 patients with cancer per practice (2350 listed patients)
- GPs take care of follow-up visits for cancer patients 5 years after the diagnosis; care of other chronic conditions, acute and general symptoms
- Cancer survivors have a higher number of visits, prescriptions, referrals
- Mean number of GP contacts per year in Dutch cancer survivors compared to age and sex matched controls without cancer from the same GP practice. Sources: aHeins et al. JCO 2012 (breast-, prostate and colorectal cancer 2-5 years after diagnosis), bRoorda et al. 2013 (breast

	Breast cancer		Prostate cancer		Colorectal cancer		All types of cancer	
	Survivor	Control	Survivor	Control	Survivor	Control	Survivor	Control
Practice visits	3,3-4,0 ^{a,b}	2,9-3,2 ^{a,b}	3,6	2,9	3,5	3,0	3,5 ^c	2,7 ^c
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 ^c	0,4 ^c
Total	5,3-6,0	4,2-4,5	5,9	4,3	5,9	4,8		

Findings – Netherlands case, the role of primary care in after care for cancer, NIVEL

- Health problems for which cancer survivors visit their GP:
 - Acute and general symptoms (pain, common infections, fatigue, constipation, anemia, treatment side effects, management of hormone therapy in breast cancer)
- Forecasts
 - Estimated increase in cancer survivors and transfer of care from specialist to GP could increase number of visits per practice from 500 (in 2010) to 850-1100 (in 2020)

Findings – Danish case, organization of cancer after care in primary care settings, Frede Olesen

- Cancer care reform (2013, implementation in 2015-2016): guidance on follow-up for each main type of cancer (individual needs assessment, follow-up plan, strategy to identify recurrence; rehabilitation, palliation, psychosocial, spiritual needs)
- Status spring 2016:
 - 19 new guidelines (8 in implementation)
 - Scope and breadth of GP involvement not agreed yet (probably GPs may expect visits on an ad hoc needs based way), same with district nurses and municipal services
 - Observations show fall in number of imaging tests and transfer of care consultations from doctors to nurses

Findings – Bulgarian case, organization of cancer after care in regional cancer centres, NCPHA

- Survey on characteristics of CCC and assessment of cancer care provided
- CCC provide in-patient and out-patient cancer care and after care; role of GPs in after care is not considered relevant
- Physician/patient ratio is low; CCCs usually don't provide psychosocial care or coordination with other health and social services on community level
- After care is considered inadequate and patients' needs unmet
- Patients are generally satisfied with the care provided; waiting times and limited resources are critical point

Findings – Bulgarian case, organization of cancer after care in regional cancer centres, NCPHA

- Future involvement of GPs:
 - regular monitoring and homecare of patients with cancer, psychosocial support, working disability assessment
- Other organizations should take care of palliation and coordination with community health and social services

Conclusions and recommendations

Experience from 5 different countries.

- Objective to provide a cancer patient pathway in after care hasn't been reached as we planned, however:
 - clear and comprehensive data have been obtained on the existence and applicability of guidelines for after-care
 - different experiences showed many challenges in cancer care

Conclusions and recommendations

Recommendations regarding comprehensive patient pathway

- seamless care, which needs to be continued across the formal institutional boundaries, is important
- patients need to be fully and comprehensively informed about the processes related to their continued care
- care should be structured around the evidence-based milestones
- recurrence identification, diagnosis of complications and recurrence prevention were identified as important elements of guidelines

Conclusions and recommendations

Recommendations regarding future development of cancer after-care

- Manage cancer as a continuous process
- Co-ordinate and organise cancer care through the creation of multidisciplinary teams at all levels and with the development of a survivorship care plan
- Co-ordinate and share information between the oncological specialised care and primary care
- Organise education and training for PCP in order to strengthen their capacity to cope with the increasing population of cancer patients in after-care
- Develop 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

Conclusions and recommendations

Recommendations regarding future development of cancer after-care

- Co-ordinate between health and other sectors

Thank You