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Patient Pathways in Oncology Care

Results of a Systematic Literature Review

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Contents

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1 Introduction

Health care systems face a broad spectrum of transition processes that necessitate comprehensive, integrated care delivery. In this context, demographic change, skilled worker shortage and an increasing number of patients with multimorbidity and chronic diseases are among the main drivers (Hujala et al., 2016; Minkman, 2012). For the latter, cancer is one of the most common and costly diseases in western countries (Banks et al., 2010; Busse et al., 2010). In order to coordinate cancer care on the national level and to increase access to quality cancer care, the implementation of Comprehensive Cancer Care Networks (CCCNs) is recommended by the European guide on quality improvement in comprehensive cancer control (Albreht et al., 2017). Such networks integrate different institutions and institutional units representing all relevant episodes for a patient's cancer care journey, i. e. research, prevention, diagnosis, treatment, follow-up, rehabilitation and end-of-life care (Albreht et al., 2017). One of the CCCNs' tasks is the provision of practical support tools. In this context, comprehensive, integrated patient pathways are recognised as a valuable approach (Albreht et al., 2017).

Against this background, the research aim is to capture the state of the art and practice of patient pathways in oncology care by means of a systematic literature review. How are existing oncological pathways represented and characterised?

2 Method

2.1 Systematic literature review

The aim of the systematic literature review was to identify and analyse existing oncological patient pathways. Therefore, the databases PubMed, Scopus, and Embase were searched. The search string comprised the three phenomena (linked by AND):

- target population (children and adults with any kind of cancer diagnosis)
- intervention (patient pathway and potential synonyms used in the literature)
- setting (a network of formal and informal care providers)

The detailed search string is documented in I.Appendix A. The search was conducted in title, abstract, and keyword fields of the databases. The initial set of results was filtered as suggested by the WP10 leaders:

- species: humans
- language: any (at least abstract in English)
- publication date: 1998 until 10/2018 (date of the search)

The inclusion criteria for the screening (title/abstract) and full-text analysis phases were:

- a specific oncological pathway is addressed and represented in any format or it can be assumed that it is documented in a cited source or article's annex
- the addressed pathway has a prospective character, i.e. functions as a process template

The exclusion criteria for the screening (title/abstract) and full-text analysis phases were:

- no specific oncological pathway is presented
- letters/ editorials

The search process is depicted in Figure 1.

The results of the scientific database search were complemented by other pathway sources as depicted in Figure 2. Altogether, 70 distinct pathways were the basis for the analysis. Pathways in use were kindly provided by WP10 members from Luxembourg, Malta, Hungary, and Germany. For the publicly available pathways provided online, which were identified by backwards searches during the full-text screening of the scientific articles, two pathways for each institution were selected randomly for the analysis. This approach is reasonable because each institution represents its pathways in the same way. Same applies for the pathways provided by WP10 members. Thus, it can be assumed that the analysis of all available pathways would not have added more value than analysing two for each institution. This resulted in 30 pathways used for examination (see I.Appendix B).

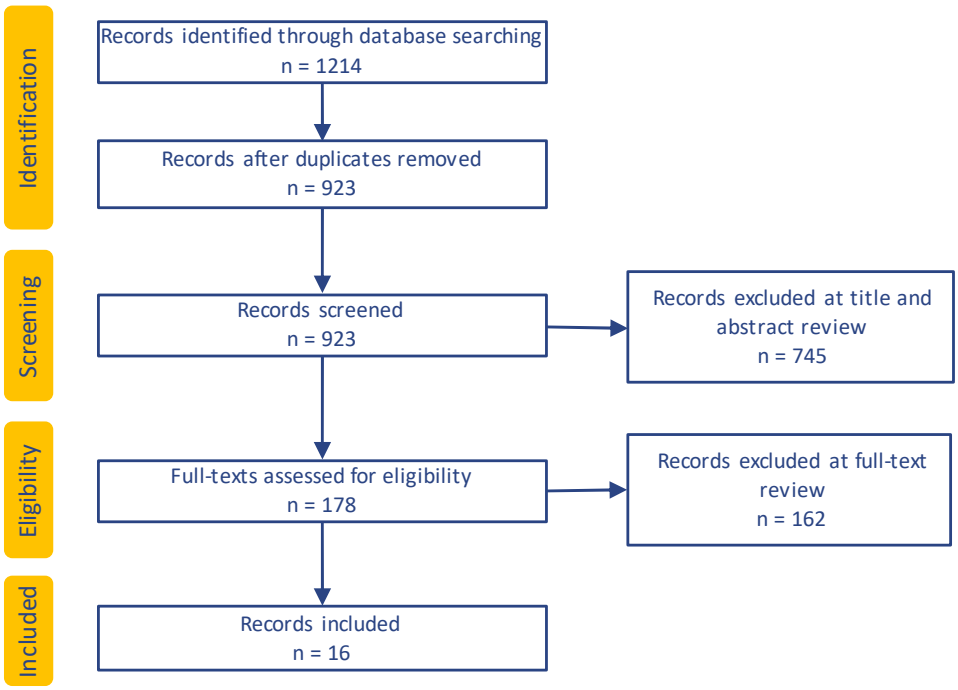

Figure 1. Search process applying the PRISMA flow chart (Liberati et al., 2009)

We analysed pathways published online by the following institutions:

- Deutsche Krebshilfe - Netzwerk Onkologische Spitzenzentren, AG Standard Operating Procedures (SOPs), Germany
- Cancer Care Ontario, Canada
- Cancer Council Victoria, Australia
- National Institute for Health and Care Excellence, United Kingdom

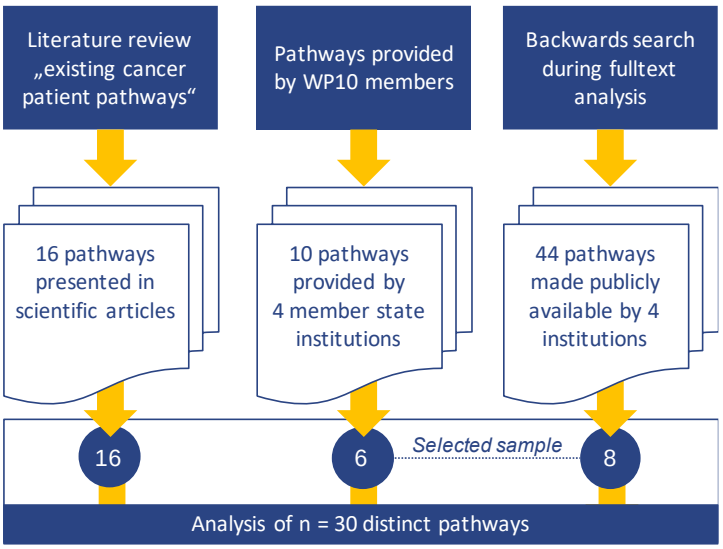

Figure 2. Sources and number of examined pathways

2.2 Pathway Analysis Scheme

For the analysis of the identified patient pathways, a set of characteristics was derived from literature on pathway auditing and evaluation as well as from the inherent characteristics that patient pathways should have as specified in based on a previous scoping review by the authors (Richter and Schlieter, 2019). The auditing and evaluation tools were identified using the results of the systematic review of (Vanhaecht et al., 2006). Four out of the seven analysed tools in this article were available and analysed in order to specify patient pathway evaluation criteria. Those are (Croucher, 2005; Mallock and Braithwaite, 2005; McSherry et al., 2003; Whittle et al., 2004). Additionally, the care pathway maturity model proposed by (Schriek et al., 2016) was used. The criteria to examine oncological patient pathways are summarised in Table 1.

Table 1. Criteria for the examination of oncological pathways

Criteria	Description
Meta-information	
Patient group (tumour entity)	Clearly defined patient group, health condition, or disease; indication of circumstances when a patient should or should not be put on the pathway (in-/ exclusion criteria)
Used pathway term	Which term is used for the presented pathway?
Design characteristics	
Representation format	How the pathway is represented
Guidance character	Defined start and end points
	Anticipated process (key components) of care along some form of timeline
	Description of cause of variance (e.g. patient-, clinical-, institution-, community/family-related) and actions to be taken
	Clarity in the decision criteria (decision moments and criteria are detailed in the pathway)
	Multidisciplinary care team (cooperation and involvement of professionals from different disciplines, informal caregivers, and patient/ family)
Scope	Scope of the pathway according to the typical phases in the cancer care process in a comprehensive network of care providers (CCCN) according to (Albreht et al., 2017): prevention, diagnosis, treatment, follow-up, palliative care/end-of-life-care, rehabilitation, research
Development	Approach or method used to develop the pathway
Reference to the evidence base	Statement of used evidence, either separately or within the pathway
Metrics definition	Degree in which metrics are used to assess achieved performance (e.g. outcomes are checked along the pathway)

Patient-centeredness	
Patient participation	Degree of involvement of patient and family in decision making; expression of opinions about different treatment methods, i.e. sharing information and knowledge, feelings/ signs, active involvement in decision processes regarding medical approach and health planning, (Ponte, Pat Reid et al., 2003; Vahdat et al., 2014), accessibility of pathway for patient (e.g. status, stages), participation during pathway design
Individualisation	To which extent the pathway places the patient in the centre of care and to which tailoring of pathway according to patient's and family's needs and preferences is addressed (e.g. aligning pathway to individual goals of care, cultural traditions, values, socioeconomic conditions)

3 Results

In the following, the results of the systematic literature review on existing oncological patient pathways are presented. The results are documented according to the criteria as defined in the pathway analysis scheme (see section 2.2).

3.1.1 Patient Group (Tumour Entity)

For a more comprehensive analysis of tumour entities, all identified pathways were included (n=70). The different cancer types addressed by these pathways are summarised in Table 2. Figure 3 depicts the frequency of occurrence of cancer types. For this purpose, all cancer types occurring only once were summarised as “others”.

Table 2. Addressed tumour entities in the examined pathways

Tumour-specific pathways (in alphabetical order), n=63	Tumour-unspecific/ community-specific pathways, n=7
bladder cancer blood and bone marrow cancers (e.g. acute myeloid leukaemia, multiple myeloma, Non-Hodgkin’s lymphoma, myeloma, Hodgkin lymphoma and diffuse large B-cell lymphoma) brain tumours and metastases (e.g. high-grade glioma) breast cancer cervical cancer colorectal cancer (also including Lynch syndrome) conjunctival melanoma endometrial cancer gastric cancer head and neck cancer (oral cancer, patients undergoing maxillofacial surgery, oropharyngeal cancer) hepatocellular carcinoma liver cancer lung cancer lymphoblastic leukaemia oesophageal cancer (incl. Barrett’s oesophagus) ovarian cancer pancreatic cancer prostate cancer renal cancer Sarcoma skin cancer (e.g. basal cell carcinoma or squamous cell carcinoma, melanoma) thyroid cancer	Aboriginal and Torres Strait Islander people with cancer complications of cancer (metastatic spinal cord compression, malignant spinal cord compression, neutropenic sepsis) metastatic malignant disease of unknown primary origin suspected cancer recognition and referral upper aerodigestive tract cancer

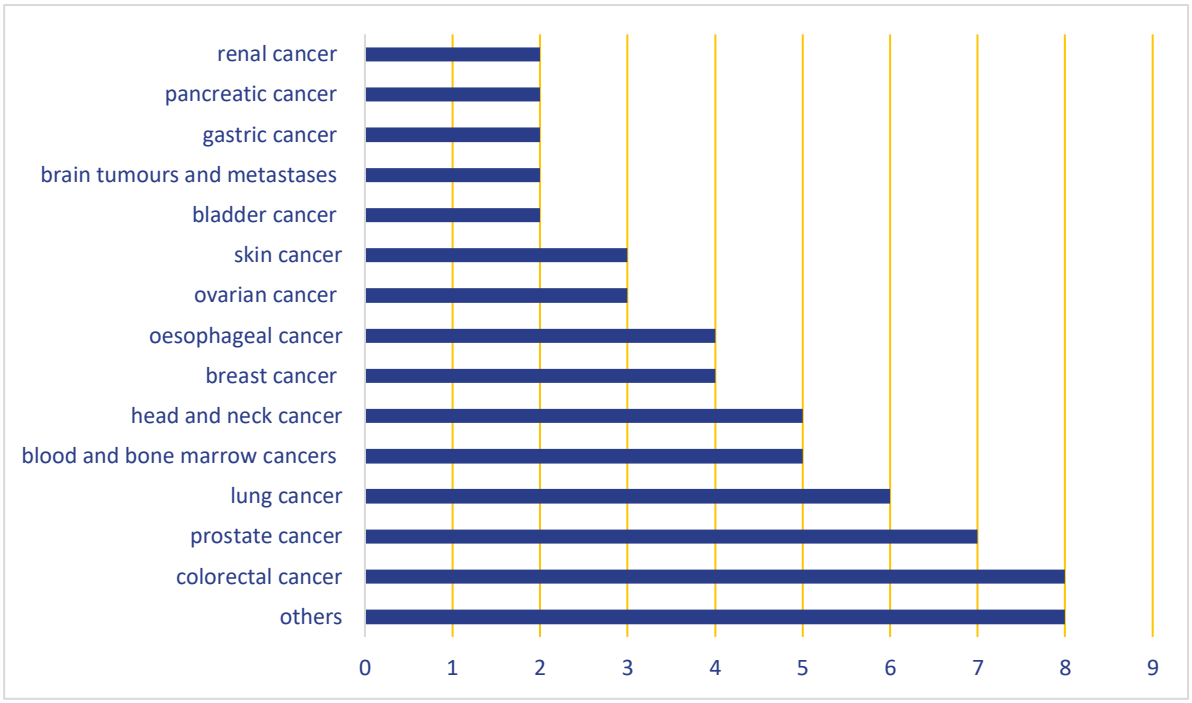

Figure 3. Number of identified tumour-specific pathways (n=63)

3.1.2 Used Pathway Terms

There are several different pathway terms used in the literature (see Figure 4). Some sources use different terms synonymously. Noteworthy, the term “patient pathway” occurred only once.

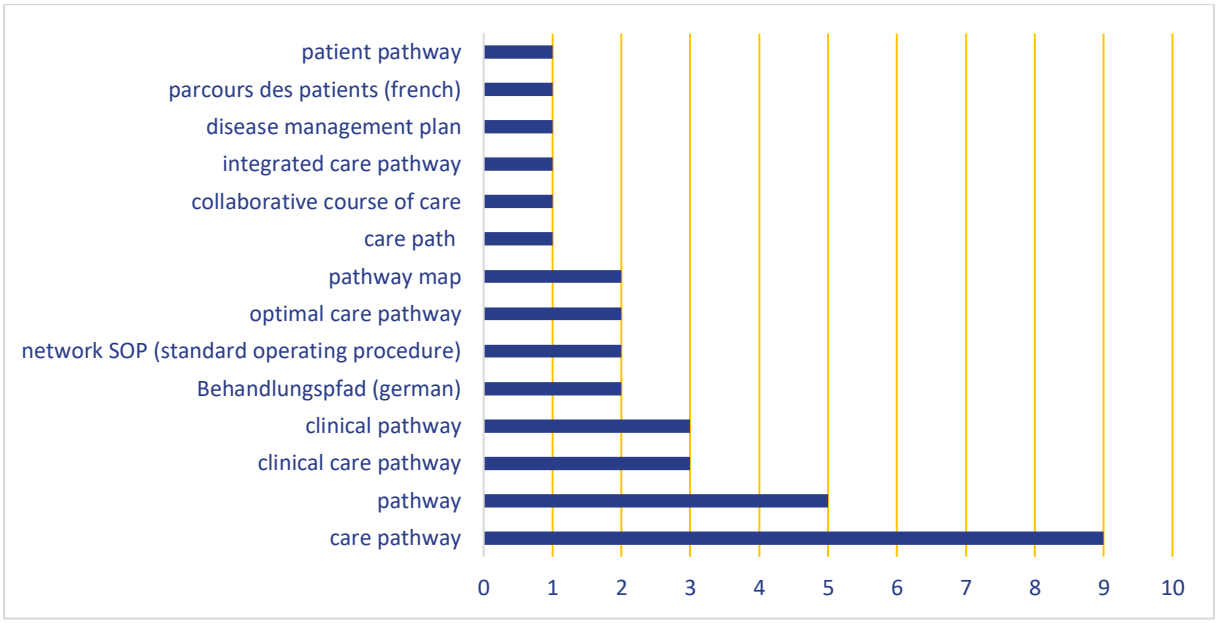

Figure 4. Terms used to label the examined pathways

3.1.3 Representation Format

The identified pathways were either represented as tables or flow charts (see Figure 5). Textual descriptions were added to both in some cases. In the case of flow charts, there is a great variety in how they are presented. It ranges from simple sequences depicted as a combination of rectangles and arrows to more complex models depicting actions/interventions, information flows, roles and responsibilities, or decision nodes, including a legend and a list of abbreviations. None of the pathways was represented using a standardised process modelling notation.

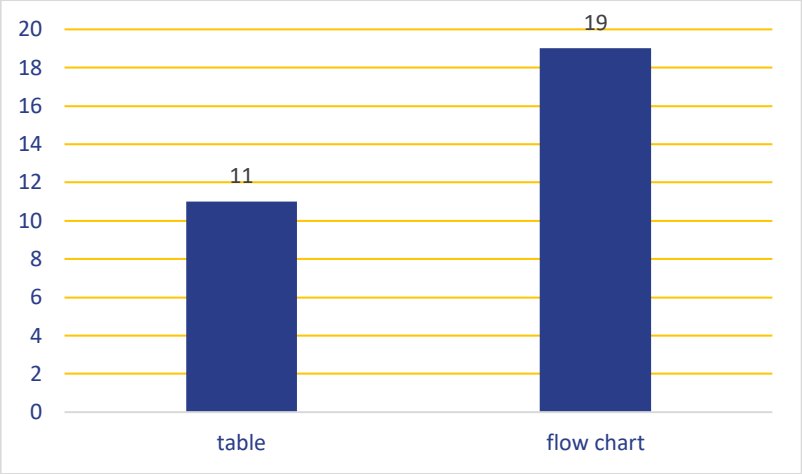

Figure 5. Representation formats of examined pathways

3.1.4 Guidance Character

All of the analysed pathways have defined **start and end points**. Also, all of them describe key components of care and represent a plan of the **anticipated process of care** in some form of a timeline. The timeline is often given on daily basis, especially in the cases of table representation. Almost all of the pathways involve a **multidisciplinary team** to perform the specified actions. The focus is on professional caregiver involvement.

None of the pathways identified with the scientific database search describe potential **variances** or causes for variances in the pathway execution. In contrast, all of the pathways provided by the WP10 members and online by international institutions (backwards search) address potential process variances, e.g. based on different clinical states of patients, disease stage, available resources (typically used treatment approach if interchangeable), or potential risks. Thus, the recognised variances in the pathways focus on clinical-, resource- and patient-related causes of variance. Community and family related causes were not identified in the analysed pathways.

The clarity of **decision criteria** is diverse. In the case of table representations, decision criteria are rather implicitly recognisable based on “if-then” or “if necessary” statements in the table text or by differentiating into different possibilities (e.g. treatment for curable and not curable patients). Flow chart representations show greater clarity in defining decision criteria, e.g. by branching the process flow and using decision nodes to describe decision moments and criteria.

3.1.5 Scope

Based on the general phases of the care process the units of a Comprehensive Cancer Care Network cover (Albreht et al., 2017), the focus of the identified pathways is on the diagnosis, treatment or follow-up phases (see Figure 6). The treatment phase is often described by pre-, peri-, and post-operative actions. As a result, pathways are often hospital-based and thus not interorganisational pathways. However, there are interorganisational pathways covering the whole cancer care continuum, starting with prevention, e.g. screening. Some even address research, e.g. by involving cancer registries or stating that patient should be offered the opportunity to participate in research activities such as clinical trials along the care pathway.

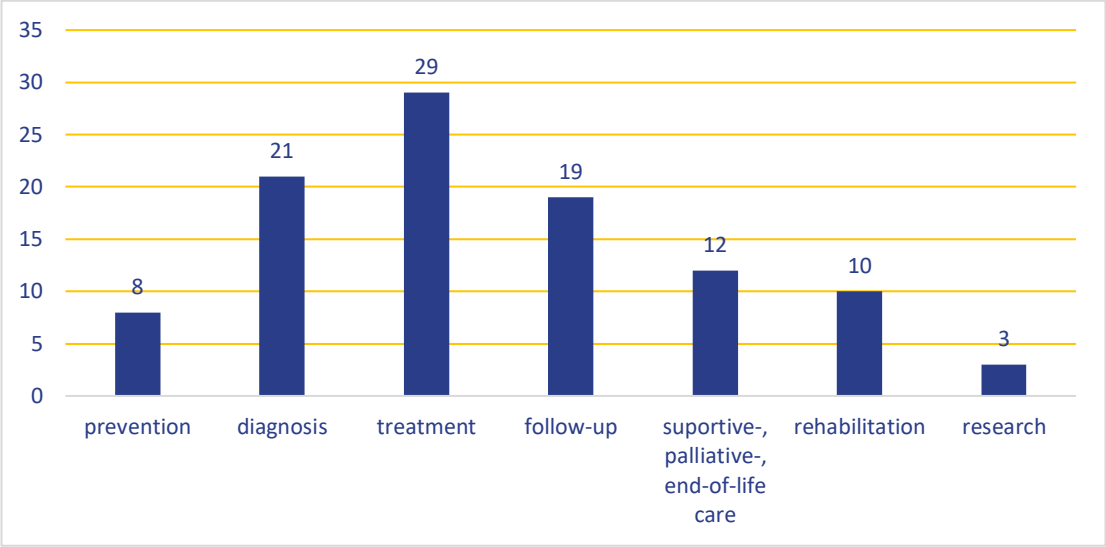

Figure 6. Phases in the care process covered in the examined pathways

3.1.6 Development

The analysed pathways were always developed by a multidisciplinary team. There was no standardised, commonly used approach for pathway development recognised. If described at all, the development consisted of a combination of different methods, which are summarized the following:

- discussions
- consensus processes
- collaborative group processes (e.g. brainstorming, diagram development)
- feedback
- internal and external reviews
- testing
- focus groups
- approval
- iterative refinement of pathway
- assessment and review to maintain currency of a pathway

The following inputs were used as knowledge base for pathway development:

- evidence from literature (studies, literature reviews, clinical practice guidelines)
- review of current practice patterns

- expert opinion, knowledge and experience from involved key personnel
- group participants consensus

3.1.7 Reference to Evidence Base

11 of the 30 examined oncological pathways included a reference to the evidence base, either in form of a general reference list or directly referenced with the described intervention.

3.1.8 Metrics Definition

Metrics for the assessment of achieved performance were defined for 17 of the 30 pathways. For the remaining pathways it was unclear, i.e. not specified in the sources, whether metrics were defined.

Primarily, there were quantitative and qualitative outcome measures (e.g. clinical outcome parameters, patient level of pain, length of hospital stay, complication rates, mortality, patient knowledge, or quality of life). Process-related measures, such as communication and coordination between caregivers or information flow were rarely included. The measures were evaluated retrospectively and mostly not directly included in the pathway. In some cases, however, optimal time frames for particular interventions defined in the pathway were annotated. Online tools such as NICE pathways describe quality standards along the pathway steps.

3.1.9 Patient Participation

In summary, 16 of 30 pathways included aspects of patient participation. They can be summarized as follows:

- patient information and education (e.g. daily routine, planned course of surgery, treatment options, disease), rarely also expanded to informing patient's family
- patient consent
- patient feedback (e.g. questionnaires)
- patient mobilisation
- counselling
- discussions

In two cases, there were patient versions of pathways (guides, leaflets) available, describing the planned course of actions for a patient.

3.1.10 Individualisation

Individualisation of pathways, i.e. allow pathway tailoring to individual patient's needs and preferences, is very limited so far. Only 4 out of 30 pathways showed options for individualisation. These options were only found in pathways provided by WP10 members and by institutional websites. For example, pathways include advice to consider co-morbidities and life expectancy of a patient when the treatment option is to be decided. Individualisation to patient preferences can also be read out of pathway progress, e.g. actions to be taken if patients decline referrals or choose a "wait-and-see" approach. In summary individualisation was addressed rather implicitly in pathways and there were no methodological approaches used in order to configure patient-individual pathways.

4 Summary

The systematic literature review gave insights into the current state of the art of patient pathways in oncology care. The key results are summarised in Table 3.

Table 3. Summary of key results regarding the research questions

Research question	Summary of key results
How are existing oncological pathways represented and characterised?	• Great number of existing pathways for diverse tumour entities • Focus rather on intra-organisational pathways and the diagnosis, treatment and follow-up phases • No common development method or representation • Patient participation mechanisms already addressed • Individualisation mechanisms call for progress

The conducted literature review showed great variance in the use of patient pathways in oncology care. A common understanding in science and practice and methodical support and standardisation for the development of patient pathways are essential to exploit their full potential in Comprehensive Cancer Care Networks. These open issues are further addressed by the work in Task 2 of the iPAAC WP10.

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Appendixes

Appendix A Search string for the systematic literature review

As indicated in section 2.1, the search string for the systematic literature review on existing oncological patient pathways comprised the three phenomena target population, intervention, and setting. They were detailed and combined with the following search string (see Table 4). The setting part was adapted from (Bautista et al., 2016), who conducted a systematic literature review to identify instruments to measure integrated care. Their search string part to describe the setting of integrated care in a network of care providers was used to define the setting for the own search.

Table 4. Search string for the systematic literature review

Target population
cancer*[Title/Abstract] OR carcin*[Title/Abstract] OR tumor*[Title/Abstract] OR neoplasm*[Title/Abstract] OR malign*[Title/Abstract] OR metasta*[Title/Abstract] OR oncolog*[Title/Abstract] OR leukem*[Title/Abstract] OR sarcoma[Title/Abstract] OR lymphoma[Title/Abstract] OR melanoma[Title/Abstract] OR blastoma[Title/Abstract] OR neoplasms[MeSH]
AND
Intervention
patient pathway[Title/Abstract] OR care pathway[Title/Abstract] OR clinical pathway[Title/Abstract] OR integrated pathway[Title/Abstract] OR care map[Title/Abstract] OR treatment pathway[Title/Abstract] OR patient journey[Title/Abstract] OR patient route[Title/Abstract] OR patient navigation[Title/Abstract] OR critical pathways[MeSH]
AND
Setting
“Continuity of Patient Care”[MeSH] OR “Continuity of care”[Title/Abstract] OR “Continuity of patient care”[Title/Abstract] OR “patient care continuity”[Title/Abstract] OR “Care continuity”[Title/Abstract] OR “Healthcare continuity”[Title/Abstract] OR “health care continuity”[Title/Abstract] OR “Service continuity”[Title/Abstract] OR “comprehensive care”[Title/Abstract] OR “comprehensive health care”[Title/Abstract] OR “comprehensive healthcare”[Title/Abstract] OR “comprehensive health services”[Title/Abstract] OR “comprehensive health service”[Title/Abstract] OR “comprehensive service”[Title/Abstract] OR “comprehensive services”[Title/Abstract] OR “comprehensive patient care”[Title/Abstract] OR “coordination of care”[Title/Abstract] OR “care coordination”[Title/Abstract] OR “Healthcare coordination”[Title/Abstract] OR “health care coordination”[Title/Abstract] OR “Service coordination”[Title/Abstract] OR “Services coordination”[Title/Abstract] OR “Service co-ordination”[Title/Abstract] OR “Coordinated care”[Title/Abstract] OR “Coordinated health care”[Title/Abstract] OR “Coordinated healthcare”[Title/Abstract] OR “Coordinated patient care”[Title/Abstract] OR “Coordinated service”[Title/Abstract] OR “Coordinated services”[Title/Abstract] OR “Coordinated care”[Title/Abstract] “Co-ordinated service”[Title/Abstract] OR “Co-ordinated services”[Title/Abstract] OR “Coordinating care”[Title/Abstract] OR “Coordinating health care”[Title/Abstract] OR “Coordinating patient care”[Title/Abstract] OR “Coordinating service”[Title/Abstract] OR “Coordinating services”[Title/Abstract] OR “Coordinating care”[Title/Abstract] OR “Co-ordinating health care”[Title/Abstract] OR “Co-ordinating

service”[Title/Abstract] OR “Co-ordinating services”[Title/Abstract] OR “Delivery of Health Care, Integrated”[MeSH] OR “Integration of care”[Title/Abstract] OR “Integration of health care”[Title/Abstract] OR “Integration of healthcare”[Title/Abstract] OR “Integration of patient care”[Title/Abstract] OR “Integration of service”[Title/Abstract] OR “Integration of services”[Title/Abstract] OR “Care integration”[Title/Abstract] OR “Healthcare integration”[Title/Abstract] OR ”health care integration”[Title/Abstract] OR “Service integration”[Title/Abstract] OR “Services integration”[Title/Abstract] OR “Integrated care”[Title/Abstract] OR “Integrated health care”[Title/Abstract] OR “Integrated healthcare”[Title/Abstract] OR “Integrated patient care”[Title/Abstract] OR “Integrated service”[Title/Abstract] OR “Integrated services”[Title/Abstract] OR “Integrating care”[Title/Abstract] OR “Integrating health care”[Title/Abstract] OR “Integrating healthcare”[Title/Abstract] OR “Integrating patient care”[Title/Abstract] OR “Integrating service”[Title/Abstract] OR “Integrating services”[Title/Abstract] OR “organizational integration”[Title/Abstract] OR “organisational integration”[Title/Abstract] OR “care network”[Title/Abstract] OR “professional integration”[Title/Abstract] OR “clinical integration”[Title/Abstract] OR “continuum of care”[Title/Abstract] OR “care continuum”[Title/Abstract] OR “continuum of services”[Title/Abstract] OR “continuum of service”[Title/Abstract] OR “service continuum”[Title/Abstract] OR “services continuum”[Title/Abstract] OR “comprehensive care”[Title/Abstract] OR “comprehensive health care”[Title/Abstract] OR “comprehensive healthcare”[Title/Abstract] OR “comprehensive health services”[Title/Abstract] OR “comprehensive health service”[Title/Abstract] OR “comprehensive service”[Title/Abstract] OR “comprehensive services”[Title/Abstract] OR “comprehensive patient care”[Title/Abstract] OR “Patient-Centered Care“[MeSH] OR “Patient centered care”[Title/Abstract] OR “Patient centered health care”[Title/Abstract] OR “Patient centered healthcare”[Title/Abstract] OR “Patient centered service”[Title/Abstract] OR “Patient centered services”[Title/Abstract] OR “Patient centred care”[Title/Abstract] OR “Patient centred health care”[Title/Abstract] OR “Patient centred healthcare”[Title/Abstract] OR “Patient centred service”[Title/Abstract] OR “Patient centred services”[Title/Abstract] OR “Patient focused care”[Title/Abstract] OR “Patient focused health care”[Title/Abstract] OR “Patient focused healthcare”[Title/Abstract] OR “Patient focused service”[Title/Abstract] OR “Patient focused services”[Title/Abstract] OR “Case Management”[MeSH] OR “Case management”[Title/Abstract]

Appendix B Examined patient pathways in the systematic literature review

In the following, the pathways examined in the systematic literature review are listed. They comprised pathways identified with the scientific database search (see Table 5), kindly provided by WP10 members (see Table 6) and pathways publicly available online (see Table 7).

Table 5. Oncological pathways identified by the systematic literature search in scientific databases

Reference	Pathway
(Gheiler et al., 1999)	prostate cancer
(McMahon et al., 2000)	children (<15) with acute lymphoblastic leukemia
(Kaltenthaler et al., 2001)	lung cancer
(Pease et al., 2004)	malignant spinal cord compression; advanced metastatic cancer
(Harris et al., 2006)	patients undergoing maxillofacial surgery
(Fischbach and Engemann, 2006)	colorectal carcinoma
(Viklund and Lagergren, 2007)	oesophageal cancer
(Siddall et al., 2012)	oral cancer
(Tarin et al., 2012)	patients undergoing open and minimally invasive kidney surgery
(Fasola et al., 2012)	non–small-cell lung cancer
(Hennink et al., 2013)	colorectal cancer, Lynch syndrome
(Van Houdt et al., 2013)	radical prostatectomy patients
(Yeung et al., 2014)	oral cancer
(Klinkhammer-Schalke et al., 2015)	colorectal cancer
(Turini et al., 2017)	prostate cancer
(van Zelm et al., 2018)	colorectal cancer

Table 6. Pathways provided by iPAAC WP10 members (underlined pathways were examined as samples)

Country	Institution	Pathway
Germany	Charité, University Medicine Berlin	gastric carcinoma
Hungary	National Institute of Oncology	renal cancer
Luxembourg	Institut National Du Cancer	prostate cancer, breast cancer, colorectal cancer, lung cancer
Malta	Cancer Care Pathways Directorate	colorectal cancer, prostate cancer, lung cancer, bladder cancer

Table 7. Institutions making oncological pathways publicly available online (underlined pathways were examined as samples)

Country	Institution	Access	Pathway
Australia	Cancer Council Victoria	https://www.cancervic.org.au/for-health-professionals/optimal-care-pathways	16 optimal cancer care pathways, sample: pancreatic cancer, colorectal cancer
Canada	Cancer Care Ontario	https://www.cancercareontario.ca/en/pathway-maps	Ovarian cancer, breast cancer, Oropharyngeal Cancer (diagnosis pathway map)
Germany	Deutsche Krebshilfe, Netzwerk Onkologische Spitzenzentren, AG Standard Operating Procedures (SOPs)	http://www.ccc-netzwerk.de/arbeitsgruppen/standard-operating-procedures/netzwerk-sops.html	conjunctival melanoma, thyroid cancer, multiple myeloma
United Kingdom	National Institute for Health and Care Excellence	https://pathways.nice.org.uk	22 cancer pathways, sample: pancreatic cancer, prostate cancer