

Paving the Way for Patient Pathways: Synthesizing a User-Centered Method Design with Results from a Systematic Literature Review

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Abstract. Patient pathways are recognized as a valuable governance instrument to increase standardization, quality, comparability, and transparency of care in comprehensive care networks. Yet, methodological support is lacking. This paper aims to support their development, implementation and continuous maintenance. Therefore, a systematic literature review of existing pathway methods was conducted and a consolidated pathway framework was derived. The framework was complemented by additional steps specific for patient pathways, which were derived in workshops with potential end users of the method proposed. Therefore, a qualitative content analysis was conducted. The additional steps emphasize the longing for generic patient pathway templates and their adaptation to national, regional, and local conditions of care networks. This work is a step forward towards standardized patient pathway development, their large-scale implementation and digitization. In the next step, the proposed method will be applied and tested in the European iPAAC Joint Action addressing innovations in cancer control.

Keywords: care networks, method development, patient pathways, systematic literature review, user requirements

1 Introduction

The increasing complexity of medical interventions and technical advancements call for a seamless coordination of the various actors involved during the entire care process of a patient. Regarding this coordination effort, integrated care has evolved as a core concept to deliver the right care to the right person at the right place and to mitigate disparities resulting from accessibility or general distribution of health care services [1]. Despite the well-elaborated conceptual foundation of integrated care [2, 3], the implementation of such comprehensive care networks is still challenging and requires high coordinative efforts. As most western health care systems are highly regulated, national or international non-profit organizations, such as cancer associations or other governmental authorities, govern the implementation processes of care networks centrally and thus define care standards, quality goals, or required

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qualification profiles for network members [4]. In cancer care, with cancer being one of the most common and costly diseases in western countries [5], patient pathways are recognized as a valuable tool to improve patient information as well as to implement medical guideline recommendations and seamless, optimal care in an integrated network of health service providers [6]. Cancer care creates a high need for intersectoral and interdisciplinary coordination between all units involved and requires long-term care along the entire continuum of care. The use of patient pathways is therefore particularly suitable for this patient group.

A patient pathway is a tool that supports the planning and management of the care process of individual patients within a group of similar patients with complex, long-term conditions [7]. A patient pathway details the phases of care, guiding the whole journey a patient takes by defining goals and milestones, and supports mutual decision-making by the patient and her/his multidisciplinary care team collaborating in a comprehensive network of care providers [7, 8]. Patient pathways comprise core concepts of other pathway concepts such as care pathways [9] and clinical pathways [10] but have a stronger focus on patient empowerment and engagement, individualization, and care continuity in a network of care providers. Such networks consist of several institutions and institutional units dedicated to all relevant episodes of care, i. e., research, prevention, diagnosis, treatment, follow-up, rehabilitation and end-of-life care [6]. With patient pathways, a governing agency is equipped with an instrument assuring the quality and compliance of care processes. Still, standardization and guidance for developing and using patient pathways in a governed network setting are lacking. In practice, the approaches used for developing and implementing pathways are highly diverse and do not allow comparison or reuse of pathways, e. g., between cancer care networks specialized in the same cancer type on a national or international level. There is a plethora of work describing the implementation and analysis of particular pathways in specific settings [8]. However, they are often based on a traditional, intra-organizational pathway understanding, where the role of patient involvement in the pathway description and the focus of implementing these pathways in a large-scale, intra-organizational setting (such as comprehensive, integrated care networks) are lacking. Methodological support to address this gap is also missing.

To address these issues, this paper aims to support the development and implementation of patient pathways in comprehensive care networks. To reach this aim, three research questions need to be answered: (RQ1) What methodological approaches for the development, implementation and usage of pathways exist in general and how can they be used for a patient pathway method, (RQ2) who are prospective users and what do they require from a methodological support for patient pathways, and (RQ3) how can a patient pathway method be designed? The investigations are practically embedded in the current iPAAC (Innovative Partnership for Action Against Cancer) Joint Action¹. This European large-scale project aims to develop innovative approaches to advances in cancer control. One of the project's aims is to govern integrated cancer care, which also applies to this paper. The findings

¹ iPAAC Joint Action project website: <http://www.ipaac.eu> (Accessed: 14.11.2019)

presented provide a literature-based and user-centered method for building patient pathways for integrated care networks, e. g., comprehensive cancer care networks (CCCNs) [6].

The remainder of the paper is structured as follows. In the next section, the methods used are described, before the results are presented in section 3. These include an overview and consolidation of the current state-of-the-art in the literature on existing pathway development and implementation approaches, the description of potential user groups and user requirements for a patient pathway method to be applied in comprehensive care networks. Based on these aspects, a corresponding method is proposed before discussing and concluding the paper.

2 Methods

2.1 Overview

Instead of developing a method from scratch, existing work was identified and enhanced with aspects characterizing patient pathways and their application in comprehensive care networks. The existing work was analyzed and consolidated by means of a systematic literature review (see section 2.2). Additional aspects were derived from a workshop with potential users. The participants formulated user stories to describe requirements for a patient pathway method (see section 2.3). Based on this data, we conducted a qualitative content analysis according to MAYRING [11]. Findings from the literature review were used to define deductive categories in a coding scheme and to analyze the data accordingly. Whenever the pre-defined categories of the coding scheme were not exhaustive, new categories were identified by an inductive analysis.

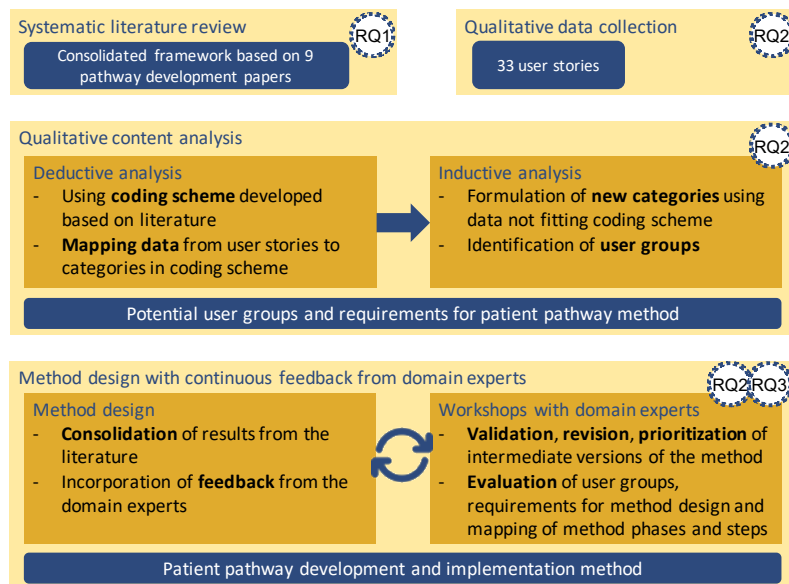


Figure 1. Overview of the research process

These categories represent aspects missing in existing pathway approaches and guide the development of the intended method for patient pathways in comprehensive care networks. Also, the potential user groups were specified inductively. The results of the qualitative content analysis, i. e., user groups and potential tasks in the patient pathway method identified, were discussed, prioritized and revised during a telephone-based workshop with four methodology- and application-oriented domain experts in cancer care in April 2019. In September 2019, final feedback was collected from the participants of an iPAAC work package meeting. Figure 1 gives an overview of the used methods and their relation to the three research questions RQ1 - RQ3. The systematic literature review and the qualitative data collection with user stories are further described in the following.

2.2 Systematic Literature Review of Existing Pathway Methods

The aim of the systematic literature review was to identify existing methods or systematic approaches for developing and implementing patient pathways (referring to RQ1). The search was performed in the databases PubMed, Scopus and AISEL. This database selection covers a broad spectrum of publications in the medical, business, management and information systems domains. The search string was defined as presented in Table 1.

Table 1. Search string used for the systematic literature review

<p>patient pathway[Title/Abstract] OR care pathway[Title/Abstract] OR clinical pathway[Title/Abstract] OR integrated pathway[Title/Abstract] OR care map[Title/Abstract]</p>
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OR treatment pathway[Title/Abstract] OR patient journey[Title/Abstract] OR patient route[Title/Abstract] OR patient navigation[Title/Abstract] OR critical pathways[MeSH Terms]		
AND		
design*[Title/Abstract] OR implement*[Title/Abstract] OR develop*[Title/Abstract] OR description[Title/Abstract] OR describ*[Title/Abstract] OR appli*[Title/Abstract] OR apply[Title/Abstract] OR build*[Title/Abstract] OR creat*[Title/Abstract] OR construct*[Title/Abstract]	AND (<i>PubMed</i> , <i>AISeL</i>) W/3 (<i>Scopus</i>)	framework[Title/Abstract] OR tool[Title/Abstract] OR approach[Title/Abstract] OR schema[Title/Abstract] OR concept*[Title/Abstract] OR manual[Title/Abstract] OR guide[Title/Abstract] OR guidance[Title/Abstract] OR steps[Title/Abstract] OR model*[Title/Abstract] OR method*[Title/Abstract]
NOT (<i>PubMed</i>)		
Clinical Study[Publication Type] OR Clinical Studies as Topic[MeSH Terms] OR Diseases Category[MeSH Terms] OR Health Care Evaluation Mechanisms[MeSH Terms] OR Environment and Public Health[MeSH Terms]		

MeSH (Medical Subject Headings) terms were only available in PubMed. The NOT-clause was developed in a pre-test to narrow down the number of results to relevant ones in PubMed (from 4.132.141 results down to 994 without any other filter). It showed that clinical studies and disease-specific publications did not meet the inclusion criteria as described below. Thus, such articles were excluded using the NOT-operator. Since Scopus does not offer similar functionalities, the WITHIN-operator (not available in PubMed) was used to closer link the phenomena describing methodological support.

The database search was conducted in the title, abstract, and keyword fields in October 2018. The results were filtered according to species (humans), language (any, at least abstract in English), and publication date (last 20 years). Additional grey literature [13] identified by a Google search was added to include pathway development methods provided or used by health care organizations. The authors independently screened the titles and abstracts. Papers were included as far as

- an approach for the development, implementation and usage of pathways (in general, not restricted to the concept of patient pathways) is described,
- an approach with guidance character is described (e. g., a method or necessary steps),
- a comprehensive approach is described.

Accordingly, articles describing the application of pathways or solely addressing single steps (e. g., pathway visualization) or derivation of pathways from clinical practice guidelines were excluded. However, they will be used later in the research process to underpin steps in the patient pathway method with specific tools.

Differences between the screening results of the two authors were solved by discussion and consensus finding. The search and screening processes and their results are shown in Figure 2.

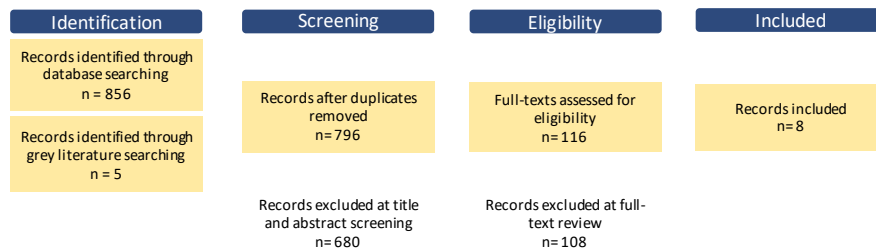


Figure 2. Process of the systematic literature review using the PRISMA flow chart [14]

2.3 Qualitative Data Collection with User Stories

When designing user-centered methods [15], the users' requirements are a necessary input. To collect user requirements, we collected user stories from the participating partners in a project meeting in February 2019. A user story is a small statement written from the perspective of the end user [16] and represents a short and informal description of a requirement. In our case, the end user refers to a user of the intended method. The user stories help identifying groups of end users, organizing the understanding of the method, and specifying user requirements. All user stories are written in the following form: "As a <role> I want <something> so that <benefit>". With this, potential users (described by the participants as role) and requirements were identified (addressing RQ2). 25 international participants took part in the meeting and represented national authorities, national and European cancer organizations, national health organizations, and research organizations. The group consisted of managers, methodologists (e. g., medical guideline developers), health care providers (e. g., oncologists, nurses), and researchers. An exemplary user story was given ("As a physician in a patient pathway development board I want to use an agreed upon pathway representation format so that all colleagues in CCCNs can exchange pathways across networks."), before all participants were asked to write down user stories either from their own or a different perspective (role). In the end, 33 user stories were collected.

3 Results

3.1 Consolidation of Existing Pathway Methods

Eight relevant articles were identified in the systematic literature review. Seven of the eight articles describe comprehensive pathway development and implementation methods or steps. The eighth is a literature review from HARKLEROAD ET AL. [17].

This review analyzed nine approaches for pathway development and their essential steps by mapping them to the most comprehensive and detailed approach at that time – the one described by GORDON [18]. Due to its early publication date, GORDON’s article was not part of our search results. However, we included it retrospectively by hand due to its comprehensiveness. In total, we analyzed nine articles (see Table 2).

All existing approaches guide the practical steps or phases of preparing, developing, implementing, maintaining, and assessing/evaluating pathways. As apparent from Table 2, the approaches address various pathway concepts (clinical care maps [19], clinical pathways [20, 21], (clinical) patient pathways [22], care pathways [20, 23], pathway maps [24], medical processes [25], and critical pathways [17]). However, the terms are neither used uniformly nor selectively. None of the approaches addresses patient pathways as defined in this article. Thus, the essential characteristics of patient engagement and pathway individualization are not covered sufficiently. Only the method described by VANHAECHT ET AL. [20] includes the patient perspective. This method includes interviews, focus groups, surveys, or walkthroughs to understand how a patient passes through a care process and to assess patient satisfaction, expectations and preferences. While existing approaches focus mainly on intra-organizational pathways, cross-organizational patient pathways are also addressed in four of the reviewed articles ([20, 21, 24, 25]).

The pathway method described by VANHAECHT ET AL. [20] is the most comprehensive and profound method so far. It consists of seven phases, which are screening, project management, diagnostic and objectification, development, implementation, evaluation, and continuous follow-up of pathways. Every phase passes through a Deming cycle (PDSA/ “plan-do-study-act” cycle). For each phase of the

Table 2. Description of the reviewed literature

<i>Source</i>	<i>Approach</i>	<i>Disease focus</i>	<i>Context</i>
McLachlan et al. (2019) [19]	Caremap development lifecycle	No specific disease focus	Single diagnostic, screening and/or intervention event
Flores et al. (2018) [21]	10-step framework to support pathway development and dissemination	No specific disease focus	Geographically distributed care settings and providers
Cancer Care Ontario (2017) [24]	Pathway map development methodology	Cancer	Cross-organizational care
Ferrante et al. (2016) [25]	Methodology to model healthcare processes	No specific disease focus	In-hospital, cross-organizational care
Vanhaecht et al. (2012) [20]	7-phase method to design, implement and evaluate care pathways	No specific disease focus	In-hospital, primary care and cross boundary projects

Wicke et al. (2004) [22]	Four phases of pathway development	No specific disease focus	In-hospital
Harkleroad et al. (2000) [17]	Review on critical pathway development (1992-1997)	No specific disease focus	No specific focus
Bisanz et al. (1999) [23]	Process for care pathway development and implementation in a comprehensive cancer center	Cancer	In-hospital/ cancer center
Gordon (1995) [18]	Steps to pathway development	Burns	Burn units

method, the reasoning when to be started, the main objectives, potential tools and instruments to be used, approximate duration, and the evaluation of the phase output are described. The method was validated by an international expert panel of the European Pathway Association. Due to the comprehensiveness of the method proposed by VANHAECHT ET AL., we decided to use it as the basis for our analysis and mapped the steps described in the other approaches accordingly (see Table 3).

The mapping provides a comprehensive framework of steps to be addressed for developing, implementing, and continuously evaluating and refining pathways. The method from VANHAECHT ET AL. [20] is complemented in each of the seven phases with further steps from the other approaches reviewed. Especially in the development phase, practical tool support seems to be missing in the pathway approaches reviewed. For this, FERRANTE ET AL. [25] used conceptual modeling to visualize pathways. The other works did not specify particular pathway development tools.

Table 3. Consolidated pathway development and implementation framework

<i>Phases in VANHAECHT ET AL. [20]</i>	<i>Mapping of the steps in the other approaches reviewed</i>
Phase 1: Screening	Focus and recognition: determine if pathway approach is appropriate [20], evaluate baseline data to identify need for pathway [18, 20] Environmental context: domain analysis, perceive significant issues [25]
Phase 2: Project management	Initiate project [21] Define care process: define clinical question/problem and project scope [21, 22], patient group (in-/exclusion criteria) and time period [20] Evaluate benefits and harms [18] Establish multidisciplinary development team [18, 19, 22, 24]: define core team and broader working group [20], appoint pathway chair [24] Train and educate team on development process [19, 20] Alignment: assure pathway project is in line with other projects [18] Set up project plan (timetable, tasks, assignments, resources) [18, 20]
Phase 3: Diagnostic & objectification	Clarify and evaluate current evidence and organization of the care process [18, 19] from four perspectives (organization and team, patient and family, available evidence (using literature reviews [18, 19, 21, 22]) and legislation, external partners) [20] Prepare continuous evaluation and improvement process: define process

<i>Phases in VANHAECHT ET AL. [20]</i>	<i>Mapping of the steps in the other approaches reviewed</i>
Phase 4: Develop- ment	and outcome indicators for pathway and variance monitoring [18, 22] from the four perspectives above [20] Select formal notation for pathway representation [25] Create pathway draft [19, 21–24] Review of pathway draft and consensus finding: consult working group/ key stakeholder [18, 20, 21], consensus finding [19, 25], internal & external validation/ review [22, 24, 25] for resource and feasibility problems [18] Refine and finalize pathway content and design [19, 21, 22] including specification of patient group, defined start and end point, tasks and key (evidence-based) interventions, final and intermediate objectives [20] Visualize pathway [22]: definition of conceptual/logical process model by a process designer [25], develop forms for documentation [18] Develop a patient version of the pathway [20] Integrate pathway in (electronic) patient record [17, 20]
Phase 5: Implemen- tation	Set up implementation plan [18, 20] Inform and educate pathway users [18, 20, 22, 23] Test/pilot the pathway for a predetermined period of time [19, 20] Post pilot review based on feedback by pathway users and pathway monitoring by core development team [19, 20, 23] Post pilot refinement of pathway [19, 20] Endorsement and approval [20, 22, 24] Implement pathway in daily practice [20] Develop messaging and dissemination strategy [21] Publication and dissemination [18, 22–24]
Phase 6: Evaluation	Evaluate usability and indicators defined (see phase 3) [18, 20–23] Variance/compliance tracking and analysis [18, 20] Communicate evaluation results [17], e. g., to multidisciplinary team and management of organization [20] Continue using pathway in daily practice in case of positive evaluation [20]
Phase 7: Continuous follow-up	Agree on responsible person/team for continuous follow-up [20] Check applicability and relevance of pathway (e. g., new evidence, organizational changes) at fixed intervals (e. g., every 6 months) [20, 22] Continuous evaluation through variance analysis and process and outcome indicators (recommendation: annually) [19, 20, 22–24] Revision and update of pathway if necessary [18, 20, 22, 24]

In summary and referring to RQ1, the framework in Table 3 consolidates existing methodological approaches. The steps identified can also be used for developing patient pathways as they comprise essential tasks and are not applicable exclusively for a particular pathway- or patient type. Instead, they are relevant for inter- as well as intra-organizational settings. However, the essential characteristics of patient pathways to be implemented in a comprehensive care network are not addressed in

detail within the existing approaches. Further specification and tool support are missing. Also, the definition of patient pathways highlights patient engagement and individualization, which are not covered in detail so far. The same applies for the governance perspective. Therefore, to address these gaps, the consolidated framework needs to be complemented by steps characterizing patient pathways specifically.

3.2 Potential User Groups and Requirements for the Patient Pathway Method

In order to identify relevant user groups (referring to RQ2) for the intended patient pathway method, we analyzed the roles mentioned in the user stories (see section 2.3). All roles were captured and classified into seven user groups:

- health service providers/ members of the comprehensive care network (e. g., network advisors, (network) quality managers, physicians, medical doctors in training, nurses),
- health care organizations (e. g., representatives of accreditation organizations or multi-disciplinary multi-stakeholder organizations),
- policy representatives (e. g., national authorities, policy developers or advisors),
- patients,
- researchers,
- technical experts, and
- methodologists.

In a second (feedback) workshop, the participants approved these user groups and emphasized that the primary users of the method are the relevant units of a care network, policy representatives, and national/international health care organizations.

To further identify requirements relevant for a comprehensive patient pathway method, we combined a qualitative content analysis with the conducted literature review. Therefore, we used the data collected with the user stories. The steps identified in the consolidated pathway development framework (highlighted in bold in Table 3) formed the categories of a coding scheme for the deductive content analysis. Due to space limitations, the coding scheme is only shown exemplarily in Table 4. Examples of the user stories assigned to the categories are also shown.

Table 4. Exemplary categories of the coding scheme used for the deductive content analysis

<i>Category</i>	<i>Definition</i>	<i>Exemplary user story</i>
Define care process	All phrases that address the definition of the clinical problem or patient group	“As a medical doctor in training I want patient pathways to be tumor-specific so that I can provide quality of care.”
Consensus finding	All phrases that address the consensus finding during development of patient pathway	“As a methodologist in a PPD [patient pathway development] board I want to have information/agreement on consensus finding process so that bias in PPD is controlled.”
Select formal	All phrases that address the	“As a technical expert in the boards I want to

notation for pathway representation	decision on how to build/visualize the patient pathway	have a clear procedural advice for building the pathway.”
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After assigning the user stories to the categories of the coding scheme, we conducted an inductive content analysis with all other phrases, which did not fit into the predefined categories, such as²:

- “As a member of a CCCN I want to have agreed upon individualized patient pathways so that I and everyone else in the CCCN knows what to do and what individually agreed upon milestones should be reached and will follow on the patient journey.”
- “As a ‘policy developer at the national level’ I want to have access to useful templates for care pathways and also examples of already delineated pathways so that colleagues with whom I work with particularly in the national health care service can be inspired/guided in the development of our own care pathways.”
- “As a quality manager I want to have a generic pathway as an example so that I/we have a frame for development of tumor specific pathways.”

With this analysis, we identified additional steps to be included in the intended patient pathway method and assigned them to the seven phases of the consolidated framework. During the expert workshops, the results of this inductive content analysis were discussed and the proposed steps were refined if necessary. The validated set of altogether 17 additional steps for the intended method is shown in Table 5. The domain experts emphasized the separation of “usage of patient pathways” as a distinct phase, after the implementation. This means to also move the step “implement pathway in daily practice” from the implementation to the usage phase and to extend the consolidated framework from Table 3 to eight phases. Furthermore, the domain experts from the user story and feedback workshops see a need for developing and using generic patient pathway templates for specific patient types. These templates shall be developed by international or national care organizations in close cooperation with all other stakeholders identified and described above. The templates need to be based on available evidence and, after approval, need to be made available publicly in an electronic patient pathway repository. A generic template would, for example, specify the main goals, phases and milestones of care as well as roles and their tasks involved in the care network. Based on adaption guidelines provided as part of the template, it shall be implemented in a comprehensive care network such as European CCCNs. Therefore, the template must be tailored to national, regional, and local specificities of that particular network. When bringing patient pathways into practice, they need to be adaptable to individual patient needs and preferences. The primary advantage of the template approach provided, according to the domain experts, is the possibility to support network governance and to increase the quality of care across different care networks for the same patient type by allowing for comparability,

² The complete list of user stories can be provided by the authors on request.

consistency, and increased uniformity of care provision. This approach results in a multi-level view on the development process, i. e., it has to be distinguished between

- (a) patient pathway template development,
- (b) patient pathway development based on an approved generic template, and
- (c) patient pathway development from scratch in case no template exists.

While the steps specific to patient pathways can be assigned to the eight phases described above, they can further be differentiated in the three development scenarios (a-c) (see Table 5). This differentiation is especially important for the development, implementation, usage, evaluation, and continuous follow-up phases. All other steps are applicable to either of the three development scenarios. The steps in the pathway framework (see Table 3) identified in the literature review need to be added to the patient pathway specific steps (see Table 5). Such, the combined table contains all required steps for the patient pathway method and distinguishes between the three scenarios (referring to RQ2 and RQ3).

Table 5. Additional steps for a patient pathway specific method

<i>Phase</i>	<i>Patient pathway specific steps</i>
Phase 1: Screening	Check electronic patient pathway repository for existing patient pathway templates and good practice implementations in other care networks
Phase 2: Project management	Disclose composition and possible conflicts of interest of the development team Define consensus finding process Establish development team consisting of representatives from all care network units involved in the care process
Phase 3: Diag. & object.	-
Phase 4: Development	(a) Develop generic patient pathway template and documentation to guide the usage of the template (b) Develop patient pathway by adaptation of approved generic patient pathway template to national, regional and local conditions of a care network (b) Document experience with template adaptation
Phase 5: Implementation	(a) Pilot generic patient pathway template in comprehensive care network(s) (a) Post pilot refinement of patient pathway template (b) Pilot template-based patient pathway in particular comprehensive care network (b) Post pilot refinement of template-based patient pathway
Phase 6: Usage	Individualize patient pathway with regard to patient individual characteristics
Phase 7: Evaluation	(a) Add generic patient pathway template and documentation of adaptation to electronic patient pathway repository (b) Add regionally adapted patient pathway to electronic

<i>Phase</i>	<i>Patient pathway specific steps</i>
	patient pathway repository (b) Add documentation of experience with template adaptation to electronic patient pathway repository (c) Propose own positively evaluated patient pathway as basis for new patient pathway template if patient type has not yet been covered in electronic patient pathway repository
Phase 8: Cont. follow-up	(a) Evaluate feedback from template adaptations

4 Discussion

In this study, we used a literature and user-centered research approach to derive steps relevant for a patient pathway method. We conducted a systematic literature review on existing pathway development and implementation approaches. The consolidated pathway development and implementation framework shows that the essential characteristics, such as patient individualization or the usage of patient pathways as a governance tool for comprehensive care networks, are not sufficiently addressed in existing approaches (answering RQ1). To identify potential user groups and verify the findings from the literature analysis, we collected user stories and analyzed the data by means of a qualitative content analysis. We identified 17 additional steps specific for patient pathway and distinguished them regarding three application scenarios as domain experts see the importance of generic patient pathway templates (answering RQ2). With the research approach chosen, a method to guide the development, usage and continuous evaluation of patient pathways and templates in comprehensive care networks was developed (answering RQ3).

Critically reflecting on the limitations of our study approach, the number of articles included in the analysis is rather small. Searching other scientific databases could have enlarged the literature base. However, a manual search in Google Scholar did not result in any additional article. This indicates that no other generic articles, which describe generic pathway development approaches, exist. Addressing the requirements analysis, the data collection with user stories could be repeated with stakeholders of other complex and chronic diseases than cancer care, e. g., diabetes, stroke care, or chronic wound care [26]. This would validate and complement the current findings.

The next steps in the research process are to further refine the concept and design of the intended patient pathway method. Existing pathway modeling approaches will be evaluated regarding their suitability for representing patient pathways. The provision of a patient pathway specific modeling language might be necessary. With regard to the major requirement of pathway reusability, configurable process models seem to be a valuable approach [27]. Especially the mechanisms of reference modeling [28] seem to be suitable. Also, the adaptation and individualization of patient pathways and templates need to be specified further. Therefore, the modification types for agile adaptation of medical processes by BURWITZ ET AL. [29] could function as a basis.

The method proposed will be tested in the context of the iPAAC Joint Action. Generic patient pathway templates for pancreatic and colorectal cancer will be developed. These templates will be adapted and implemented in two CCCN pilot sites in Poland and Germany. Therewith, the currently rather unspecific tasks regarding pathway (draft/template) development and adaptation will be specified, e. g., by guiding the method user in defining specific concepts in the pathway and including the care network context. For the testing, iterations of close feedback loops with a working group of domain experts involving all relevant stakeholder groups in cancer care will be implemented. Based on the experiences and lessons learned during the testing and implementation phases, the method will be further improved, especially with regard to its practical applicability. The continuous evaluation of the method in its organizational context will ensure the development of a useful and applicable solution.

5 Conclusion

The presented work addresses the challenge of governing comprehensive care networks. Patient pathways were recognized as a valuable instrument with the potential to increase standardization, quality, comparability, and transparency of care provision in such networks, e. g., cancer care networks [6]. However, there has not been sufficient methodological support to truly utilize their potentials so far. Existing pathway development approaches do not fully cover the requirements of patient pathways as defined in this article. We used a literature and user-centered research approach to derive relevant steps in a patient pathway method. With the method provided, the development, implementation and continuous usage of patient pathways is structured. It will be tested by implementing template-based patient pathways for two tumor entities in two European CCCNs. The tested method will be part of the certification program in European cancer care, underlining its high dissemination potential. The method will be publicly available as part of the main output of the Joint Action - a roadmap on implementation and sustainability of cancer control actions. The work is a step forward towards standardized patient pathway development and their large-scale implementation in comprehensive care networks. With the patient pathway method, European CCCNs and cancer governance strive for improved patient care based on comparable care processes of uniformly high quality. The method can increase the practical application of patient pathways and serve as basis for their evaluation.

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References

1. Lerum, S.V., Frich, J.C.: Normative assumptions in integrated care: A conceptual discussion. *International Journal of Healthcare Management* 5, 32–39 (2012)
2. Valentijn, P.P., Schepman, S.M., Opheij, W., Bruijnzeels, M.A.: Understanding integrated care: a comprehensive conceptual framework based on the integrative functions of primary care. *Int J Integr Care* 13, e010 (2013)
3. Minkman, M.: The Development Model for Integrated Care: a validated tool for evaluation and development. *Journal of Integrated Care* 24, 38–52 (2016)
4. 6, P., Peck, E., Goodwin, N.: Managing across diverse networks of care: lessons from other sectors. Presented at the International Journal of Integrated Care, 4th Annual Conference, Birmingham Botanical Gardens, Birmingham, UK, February (2004)
5. Busse, R., Blümel, M., Scheller-Kreinsen, D., Zentner, A.: Tackling chronic disease in Europe. Strategies, interventions and challenges, Copenhagen (2010)
6. Albrecht, T., Kiasuwa, R., Van der Bulcke, M. eds: EUROPEAN guide on quality improvement in comprehensive cancer control. Ljubljana: National Institute of Public Health; Brussels: Scientific Institute of Public Health (2017)
7. Richter, P., Schlieter, H.: Are you on the (path)way yet? A survey examining the understanding and implementation of oncological patient pathways among members of the Innovative Partnership for Action Against Cancer (IPAAC) joint action. *Forum* 105 (2019)
8. Richter, P., Schlieter, H.: Understanding Patient Pathways in the Context of Integrated Health Care Services - Implications from a Scoping Review. In: Proceedings der 14. Internationalen Tagung Wirtschaftsinformatik., pp. 997–1011, Siegen (2019)
9. Schrijvers, G., van Hoorn, A., Huiskes, N.: The care pathway: concepts and theories: an introduction. *Int J Integr Care* 12, (2012)
10. Kinsman, L., Rotter, T., James, E., Snow, P., Willis, J.: What is a clinical pathway? Development of a definition to inform the debate. *BMC Medicine* 8, 31–33 (2010)
11. Mayring, P.: Qualitative Content Analysis. *Forum: Qualitative Social Research* 1 (2), 1-10 (2000)
12. Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G.: Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *BMJ* 339, (2009)
13. Tillett, S., Newbold, E.: Grey literature at The British Library: revealing a hidden resource. *Interlending & Document Supply* 34 (2), 70–73 (2006)
14. Liberati, A., Altman, D.G., Tetzlaff, J., Mulrow, C., Gøtzsche, P.C., Ioannidis, J.P.A., Clarke, M., Devereaux, P.J., Kleijnen, J., Moher, D.: The PRISMA Statement for Reporting Systematic Reviews and Meta-Analyses of Studies That Evaluate Health Care Interventions: Explanation and Elaboration. *PLOS Medicine* 6, e1000100 (2009)
15. Iivari, J., Iivari, N.: Varieties of User-Centeredness. In: Proceedings of the 39th Annual Hawaii International Conference on System Sciences (HICSS'06). pp. 176a–176a (2006)
16. Ambler, S.W.: Introduction to User Stories. Initial User Stories (Formal), <http://www.agilemodeling.com/artifacts/userStory.htm#InitialFormal> (Accessed 02.08.2019)
17. Harkleroad, A., Schirf, D., Volpe, J., Holm, M.B.: Critical pathway development: An integrative literature review. *Am. J. Occup. Ther* 54, 148–154 (2000)
18. Gordon, M.: Steps to pathway development. *J Burn Care Rehabil.* 16, 197–202 (1995)

19. McLachlan, S., Kyrimi, E., Dube, K., Fenton, N.: Clinical Caremap Development: How can caremaps standardise care when they are not standardised? In: Proceedings of the 12th International Joint Conference on Biomedical Engineering Systems and Technologies, Prague (2019)
20. Vanhaecht, K., Gerven, E.V., Deneckere, S. et al.: The 7-phase method to design, implement and evaluate care pathways. *The International Journal of Person Centered Medicine* 2, 341–351 (2012)
21. Flores, E.J., Mull, N.K., Lavenberg, J.G., Mitchell, M.D., Leas, B.F., Williams, A., Brennan, P.J., Umscheid, C.A.: Using a 10-step framework to support the implementation of an evidence-based clinical pathways programme. *BMJ Qual Saf.* bmjqs-2018-008454 (2018)
22. Wicke, C., Teichmann, R., Holler, T., Rehder, F., Becker, H.D.: Design and use of patient pathways in general surgery. *Chirurg* 75, 907–915 (2004)
23. Bisanz A., DeJesus Y., Saddler D.A.: Development, implementation, and ongoing monitoring of pathways for the treatment of gastrointestinal cancer at a comprehensive cancer center. *Gastroenterol Nurs* 22, 107–114 (1999)
24. Cancer Care Ontario: Pathway Map Development Methodology. Document developed and maintained by the Disease Pathway Management Program (2017)
25. Ferrante, S., Bonacina, S., Pozzi, G., Pincioli, F., Marceglia, S.: A design methodology for medical processes. *Appl. Clin. Informatics* 7, 191–210 (2016)
26. Przysucha, M., Vogel, S., Hüasers, J., Wache, S., Sellemann, B., Hübner, U.: Requirements for Collaborative Decision Support Systems in Wound Care: No Information Continuity Without Management Continuity. *Stud Health Technol Inform.* 253, 133–137 (2018)
27. La Rosa, M., ter Hofstede, A.H.M., Wohed, P., Reijers, H.A., Mendling, J., Van der Aalst, W.M.P.: Managing Process Model Complexity via Concrete Syntax Modifications. *IEEE Transactions on Industrial Informatics.* 7, 255–265 (2011)
28. Becker, J., Delfmann, P., Knackstedt, R.: Adaptive Reference Modeling: Integrating Configurative and Generic Adaptation Techniques for Information Models. In: *Reference Modeling*, pp. 27–58 (2007)
29. Burwitz, M., Schlieter, H., Esswein, W.: Agility in medical treatment processes – A model-based approach. *Proceedings of Modellierung 2012*, pp. 267–279 (2012)