Patient Pathways in Integrated Care – Understanding, Development and Utilisation

by

Peggy Richter, M.Sc.

Doctoral Thesis

submitted to the

Faculty of Business and Economics
Technische Universität Dresden

in partial fulfilment of the requirements for the degree of

Doctor rerum politicarum
(Dr. rer. pol.)

Date of submission: 24.03.2021

Date of defence: 05.11.2021

Supervised by:

Prof. Dr. Werner Esswein

Prof. Dr. Susanne Strahringer

Acknowledgements

shaped and supported this topic since our initial brainstorming discussions in 2013 and enabled its application in the context of cancer care.

I am particularly grateful to my family and friends, who have always been supportive of my academic career. I would like to thank my dear friends Kristin and Willi as well as Anne and Mike for taking time to proofread my writing. I would especially like to thank my husband Robert, who encouraged me to start studying Wirtschaftsinformatik in the first place. He has always listened to my concerns – major and minor – and was a constant source of support, advice and motivation throughout the entirety of my academic education. I dedicate this work to him and to our children Emil, Margarethe and August, who provide me the necessary and refreshing balance to scientific work, as well as to my parents Karin and Bernd, whom I thank from the bottom of my heart for their everlasting support.

#doctoralthesis #patientpathways #network #thankyou #Care4Saxony
@ipaac_project @FollowHelict @TUDresden_de

Contents

List of Figures

List of Tables

List of Abbreviations

AR	Acceptance rate
BPMN	Business Process Model and Notation
CCCN	Comprehensive cancer care network
Con-#	Contribution (no. #)
DOIS	Design-oriented information systems
DSR	Design science research
iPAAC	Innovative Partnership for Action Against Cancer
IS	Information system(s)
P#	Paper (no. #)
PP	Patient pathway (used in figures only)
QI	Quality indicator
RO#	Research objective (no. #)
RQ#	Research question (no. #)
US#	User story (no. #)

Part I
Synopsis of the Doctoral Thesis

1 Introduction

1.1 Background

Patient-centredness and patient empowerment have been gaining importance in health policy and society already since the 1990s (Fumagalli et al. (2015), Castro et al. (2016)). For example, increasing patient empowerment has been one of the declared national health objectives in Germany since 2003 because patient orientation and participation provide important impulses for a demand-oriented and efficient design of healthcare systems and services (Bundesministerium für Gesundheit (2018)). A transition is taking place from an institution-based view of care provision to a more patient-based view that considers patients as co-managers of their individual care process and well-being (Kayser et al. (2019)). This transition also encompasses the developments towards **integrated care**[1], i. e. a closer coordination between inpatient, outpatient and home care services, broadening the traditional focus from acute care to better integrate health-promoting, preventive and post-treatment or palliative services as part of the whole continuum of care across sector boundaries (Minkman (2012), World Health Organization (2016), Expert Group on Health Systems Performance Assessment (2017)). These developments are particularly relevant for patients with long-term, chronic diseases or multimorbidities as their needs are often more complex and not exclusively medically determined (Smith and O'Dowd (2007), Hujala et al. (2016)).

To address the complexity of both disease and care provision, integrated care is implemented on organisational level by means of integrated care networks (Valentijn et al. (2013)). A **health care network** is a finite set of actors (people, organisational units, organisations) that cooperate to achieve their common goals in a more effective and efficient way by exploiting synergies in the provision of care for a defined patient type (Albreht et al. (2017), Alexander et al. (2003)). To this end, it is necessary to provide suitable methods, infrastructures and organisational models to enable and improve networking within and between the sectors of a health system (Kodner and Kyriacou (2000), Kodner and Spreeuwenberg (2002)). The foundation to ensure high quality care are **clinical practice guidelines** (also called medical guidelines). They identify and summarise the best medical evidence for the care of certain health problems (Kopp et al. (2002)). However, as documents comprising several hundred pages, they are not designed to centrally describe and guide the coordinated care process within a particular integrated care network in a comprehensible manner both from the provider and the patient point of view (Ollenschläger et al. (2001), Francke et al. (2008)). This also hinders rapid information provision at the time of need – for example, decision situations or an outlook on the possible further course of the individual care process. To foster patient-centred care, organisational structures

---

[1]Bold type is used for highlighting in the text.

and processes constitute an important domain of action (Bokhour et al. (2018)).

1.2 Subject and Motivation

Given the background described in section 1.1, the definition and agreement on evidence-based, multidisiplinary care pathways for a specified patient group including an assessment of their individual needs is recognised as an important quality element for integrated care networks (Minkman (2016)). Pathways in health care are used to define and manage the care process, i. e. key elements and goals of care provision for a certain patient group, involving an interdisciplinary team of care providers (De Bleser et al. (2006)). In the context of patient-centred, integrated care, such pathways are often referred to as **patient pathways** (e. g. Albreht et al. (2017), Mould et al. (2010)). The work of this doctoral thesis is motivated by the following three major fields of action stemming from current problems with regard to patient pathways.

Field of action A – Inconsistent understanding and use of the term. There is a multitude of pathway terms used in literature and practice, leading to a heterogeneous understanding of patient pathways. For example, treatment pathway, care pathway and patient journey are terms used interchangeably in the patient pathway literature (Richter and Schlieter (2019c)). Other pathway terms such as clinical pathway, critical pathway, integrated care pathway or care map (De Luc (2001)) further add to the confusion. They are united by the underlying pathway approach of structuring the care process for a defined patient type based on current evidence but partly have differing focuses. A clear terminological delimitation to other pathway approaches is also missing for patient pathways, as is their characterisation and definition. This leads to misunderstandings and wrong applications of the term in both science and practice. Thus, a uniform understanding of patient pathways is required.

Field of action B – Insufficient implementation and comparability. Pathways are considered useful for the implementation of care standards into local care structures, e. g. based on the recommendations of clinical practice guidelines (Kinsman et al. (2010)). There is already a considerable number of publications describing the development and implementation of particular pathways in specific settings as in general surgery or specialist care (e. g. Wicke et al. (2004), Greenwood (2006)). However, they often follow a rather traditional, intraorganisational pathway understanding with low consideration of interorganisational interactions along the whole continuum of care as well as the inclusion of a patient view. Consequently, methodical support for the development and implementation of patient pathways is insufficient. Furthermore, as pathway development for integrated care networks is neither standardised nor centrally organised, e. g. as part of the implementation strategy of clinical practice guidelines, there is also no mechanism available to govern the translation of guideline specifications into everyday care processes or to check their compliance. Similarly, due to the lack of a uniform

development method, the comparability of patient pathways across different care networks is hampered. Thus, methodical support for the development and implementation of patient pathways is needed.

Field of action C – Lack of linkage to quality specifications. The utilisation of patient pathways is a means to improve the quality of integrated care settings (Minkman (2016)). To support the achievement of quality objectives defined for an integrated care network, appropriate actions that represent corresponding quality specifications can be defined in pathways. For example, quality indicators representing the fulfilment of guideline recommendations are in some cases already defined as part of clinical practice guidelines. However, these quality specifications are yet not explicitly represented in pathways. This limits the opportunity to expand their current outcome-based quality orientation by procedural aspects of the patient pathway (Beckmann et al. (2016)) and to utilise them for pathway-based quality monitoring, continuous quality management of integrated care networks or network benchmarking and governance (Richter et al. (2016)). Since process interventions are the vehicles to improve outcomes, the use of process measures to assess quality of care is advisable (Brook et al. (2000)). Therefore, the quality of care in an integrated care setting is not exclusively determined by indication-specific measures but should also include general measures, e.g. in the realms of patient-centredness, interprofessional teamwork or care coordination (Minkman et al. (2009)). To do so, it still needs to be clarified which quality aspects constitute process quality in integrated care settings. Overall, a means for the utilisation of patient pathways for quality management purposes with a focus on process measures is desirable.

Motivated to deeper investigate solutions to the problems described by these three action fields, this doctoral thesis strives for unifying the understanding of patient pathways and for methodically supporting their development and utilisation in integrated care networks. The work is embedded in the contexts of two funded research projects – the Junior Research Group Care4Saxony[2] and the European Joint Action iPAAC[3] (Innovative Partnership for Action Against Cancer). This project constellation allowed for a broad diffusion and communication of the research results on a national and European level.

1.3 Example Case

The iPAAC project opened up the application domain of integrated cancer care for this thesis. Cancer is a long-term, often highly complex disease with a number of comorbidities and one of the most common and costly diseases worldwide as well as a leading cause of death (Sung et al. (2021)). To meet the high requirements of specialised, intersectoral and interdisciplinary care for cancer patients, cancer care networks are being established. Such networks are named

---

[2]Project website: `www.care4saxony.de` (last accessed: 24.02.2021).

[3]Project website: `www.ipaac.eu` (last accessed: 24.02.2021).

comprehensive cancer care networks (CCCNs) – highlighting the integrated care value of comprehensiveness, i. e. the availability of a wide service range, customised to evolving needs and preferences of patients and their relatives (Zonneveld et al. (2018)). In CCCNs, multidisciplinary and tumour-specific care teams of multiple institutional units work together, covering the whole continuum of cancer care – from prevention, diagnosis, treatment, follow-up, rehabilitation and supportive care to palliative and end-of-life care as well as research (Albreht et al. (2017)). For example, in Germany this development is manifested in the establishment and certification of cancer centres already since the beginning of the 2000s (Kowalski et al. (2017)). Although the current medical knowledge is prepared in a highly standardised way in oncological clinical practice guidelines, which are also provided by means of patient guidelines (Langer and Follmann (2015)), the individual journey of a patient through a CCCN remains complex and not centrally organised. This makes oncology care a well suited application domain for the development, implementation and utilisation of patient pathways.

2 Research Design

With the definition of the research design, all relevant parameters for the research process and its understanding within the research community are disclosed to make results transparent, interpretable and comparable (Becker et al. (2003)). According to the research design framework of Becker et al. (2003), which offers an appropriate level of timeliness and comprehensiveness (Braun and Esswein (2006)), a research design contains the description of three main parameters – the researcher's position regarding the philosophy of science, the research objectives pursued and the research methods used. For this thesis, they are characterised as follows.

2.1 Philosophy of Science

A researcher's basic position in terms of the philosophy of science is described by his or her epistemological and ontological position as well as with the determination of the concept of truth (Becker et al. (2003), Braun and Esswein (2006), Niehaves (2005)). The central epistemological question to be answered concerns the relationship of an object of cognition to the cognition obtained by a subject (Niehaves (2005)). The ontological position of a researcher discloses the way in which a reality is assumed to exist beyond the realms of cognition and imagination of the individual subject (Becker et al. (2003)). The concept of truth addresses the question of how "true" cognition is achieved (Niehaves (2005)).

In this thesis, the epistemological position of moderate constructivism is taken, i. e. cognition is assumed to be subject-dependent. The author takes an open ontological position, whereby the existence of a "real" world independent of human cognition is neither negated nor assumed. Furthermore, the author follows the consensus theory of truth, assuming that a statement is true for a group of people, if the group accepts it to be true (Becker et al. (2003), Becker et al. (2004), Niehaves (2005)).

2.2 Research Objectives

Addressing the fields of action explained in chapter 1.2, the overall research objective of this doctoral thesis is summarised as follows.

> **Overall research objective:** to unify the understanding of patient pathways and to methodically support their development and utilisation in integrated care networks.

This overall research objective is divided into three subordinate objectives (RO) to further structure this thesis. Each of the subordinate research objectives addresses one of the fields of action described in section 1.2. To achieve the objectives, corresponding research questions (RQ) have been specified as shown in Table 1.

Table 1: Research questions in relation to the research objectives.

Overall research objective: to unify the understanding of patient pathways and to methodically support their development and utilisation in integrated care networks.	
Field of action A – Inconsistent understanding and use of the patient pathway term.	
RO1 Understanding of patient pathways	**RQ1.1 – State of the art.** How has the literature on patient pathways developed over the years and which themes are addressed in the literature?
	RQ1.2 – Characterisation. What are characteristics of patient pathways including characteristics that differentiate them from other pathway approaches?
	RQ1.3 – Assessment and state of the practice. How do stakeholders from practice assess the patient pathway approach and what is the state of practice?
Field of action B – Insufficient implementation and comparability of patient pathways.	
RO2 Methodical support for development and implementation	**RQ2.1 – Consolidation of existing approaches.** Which methodical approaches for the development, implementation and usage of pathways exist in general and how can they be used for a patient pathway method?
	RQ2.2 – Design requirements. Who are prospective users and what do they require from a methodical support for patient pathways?
	RQ2.3 – Method design. How can a patient pathway method be designed?
Field of action C – Lack of linkage between patient pathways and quality specifications.	
RO3 Utilisation for quality representation	**RQ3.1 – Quality classification.** What are process-relevant quality aspects for health care networks and how can they be classified?
	RQ3.2 – Conceptual integration. What are the relevant concepts for the integration of quality indicators in conceptual pathway models?
	RQ3.3 – Quality modelling in pathways. How can a quality perspective be integrated in conceptual pathway models?

With the first **research objective RO1**, overcoming the inconsistency and uncertainty of the understanding and use of the patient pathway term in the literature and practice is aimed at (referring to the field of action A – inconsistent understanding and use of the term). This shall be achieved by analysing the state of the art and practice of patient pathways to provide uniform characteristics of this pathway approach and to finally give a definition of the term – grounded in the literature and consented in practice (answering RQ1.1 to RQ1.3). Building on this, the second **research objective RO2** aims at providing methodical support for patient pathway development and implementation in the context of integrated care networks (referring to the field of action B – insufficient implementation and comparability). In this regard, a patient pathway method shall be developed by applying a user-driven, requirements-based development approach (answering RQ2.1 to RQ2.3). The third **research objective RO3** especially focusses on the utilisation of patient pathways for process-based quality management of integrated care networks (referring to the field of action C – lack of linkage to quality specifications). In this

	Comprehension objective	Design objective
Methodical focus	Understanding methods and techniques for IS design	Developing methods and techniques for IS design
	Understanding of patient pathways (RO1)	**Method for patient pathway design and utilisation (RO2, RO3)**
Content- and functional-driven focus	Understanding business application systems and their field of application	Provision of IS reference models for distinct companies or industries

Figure 1: Classification of the research objectives according to Becker et al. (2003).

context, the patient pathway method shall be complemented by providing a means to represent relevant quality aspects for integrated care settings in conceptual patient pathway models (answering RQ3.1 to RQ3.3).

According to the classification framework for research objectives in the field of Wirtschaftsinformatik research provided by Becker et al. (2003), this work's overall objective classifies as comprehension and design objective with methodical focus (see Figure 1). The methodical focus refers to the understanding and development of methods and techniques for the description, development, implementation and use of information systems (IS). Although the research objectives address a particular application domain, they are generic and holistic in nature. This means, that the intended clarification of and methodological support for patient pathways in integrated care networks is not meant to be specific to a particular network or patient type. Integrated care networks in general are the IS of interest in this doctoral thesis (further elaborated on in section 2.3). Therefore, the methodical focus of this work's objectives is a reasonable classification. The subordinate research objectives RO2 and RO3 map as design objectives, whereas RO1 maps as comprehension objective.

2.3 Research Methods

The position regarding the philosophy of science in section 2.1 and the formulation of the research objectives in section 2.2 determine the choice of research methods. As the overall research objective is design-oriented, the design science research (DSR) paradigm is followed for the work of this thesis. The DSR paradigm is characterised by the creation of innovative design artefacts, i.e. constructs, methods, models or instantiations (March and Smith (1995)), with the intention to answer questions contributing to solving real-world problems (Hevner et al. (2004), Hevner and Chatterjee (2010)). In this regard, the main design artefact of the DSR work in this

Contextual environment

Application domain
Integrated care networks as information systems
<u>People:</u> Health care providers, patients, managers
<u>Organisational systems:</u> Care facilities, integrated care networks, care processes
<u>Technical systems:</u> Hospital information systems, digital health applications
<u>Problems & opportunities:</u> Fields of action A - C (inconsistent understanding of PPs, lacking methodical support for PP development, implementation and their utilisation in the context of quality management for integrated care networks)

Needs, requirements

Relevance cycle

Field testing of method

Design science research

Build design artefact
Patient pathway method: Development and implementation of PPs, utilisation for quality representation

Design cycle

Evaluate in application domain

Additions to knowledge base

Rigor cycle

Grounding

Knowledge base

Foundations
<u>Scientific theories and methods:</u> Pathway definitions and development methods, reference modelling, process (pathway) modelling languages, conceptualisations of care quality (esp. quality of integrated care), performance-, process- and indicator modelling
<u>Experiences & expertise, artefacts & processes:</u> State of the art of application domain (e. g. existing pathways, quality indicator development methods; medical guidelines as basis for quality- and pathway specifications)

Figure 2: Design science research cycles according to Hevner (2007) applied to this work's field of research.

thesis is a patient pathway method that supports the development and implementation of patient pathways and provides means to utilise them for quality management purposes in integrated care networks. According to Hevner (2007), DSR is constituted by three closely related activity cycles. The design cycle is an iteration of designing and evaluating the intended artefact. The contextual environment is embedded in the design process in terms of requirements input and testing the artefact in the environmental setting (relevance cycle). The knowledge base is embedded by grounding the process of artefact design in scientific theories and methods as well as domain experiences and expertise and by adding new knowledge generated with the research (rigor cycle) (Hevner (2007)). The interrelations of the DSR cycles of this thesis' work are shown in Figure 2[4].

The work of this thesis belongs to the DSR genre of design-oriented information systems (DOIS) research, describing the German disciplin of "gestaltungsorientierte Wirtschaftsinformatik" (Peffers et al. (2018)). According to Österle et al. (2011), IS are the research object of this genre. IS are socio-technical systems comprising three object types, which are human task bearers (people), technical task bearers (information and communication technologies) and organisational concepts (functions, structures, processes) as well as their interrelations (Österle et al. (2011)). Addressing patient pathways in integrated care networks, this doctoral thesis focusses on process design for IS. DOIS research generally aims at developing and providing instructions for the design and operation of IS as well as for innovative concepts for IS, with utility for practice as the major measure. The artefacts resulting from DOIS research should comply

---

[4]The term "patient pathway(s)" is abbreviated with PP(s) in most figures of this doctoral thesis due to limited text space in illustrations.

with the four basic principles of abstraction, originality, justification and benefit (Österle et al. (2011), Peffers et al. (2018)). These principles imply the following requirements for this work's design artefact, i. e. the patient pathway method.

- **Abstraction** (i. e. the artefact is applicable to a problem class): The patient pathway method must be applicable to integrated care networks in general, independent of the patient type(s) addressed by the network.

- **Originality** (i. e. the artefact substantially contributes to the knowledge base): The patient pathway method must add to the IS theories and method knowledge base, i. e. to the comprehension of patient pathways, the methodical support of their development, implementation and their utilisation for the representation of quality aspects in conceptual pathway models.

- **Justification** (i. e. the artefact is justified and allows validation): The design of the patient pathway method must be justified using deductive and/or inductive reasoning, i. e. deriving requirements for the method design from the domain experts and/or the existing literature body (e. g. existing theories and models). Defined requirements allow for the method's validation.

- **Benefit** (i. e. the artefact is beneficial for the stakeholder groups): Validation of the patient pathway method must show if it yields benefits for the respective stakeholders.

There are several approaches aiming to specify and structure a DSR process (e. g. Peffers et al. (2007) or Offermann et al. (2009)). However, there is no indisputable way to conduct DSR research and no complete DSR method set. Instead, an individual configuration of multiple research methods can be used to run the design, relevance and rigor cycles along the major phases of a DSR project, depending on the particular research objectives (Frank (2007a)). To frame the DSR research process of this doctoral thesis, the four basic DOIS research phases described by Österle et al. (2011) are used – analysis, design, evaluation and diffusion. These four phases are also inherent in the DSR research processes suggested by Peffers et al. (2007) and Offermann et al. (2009). The description of this thesis' research process and the methods used in the four research phases are depicted in Figure 3. The selected research methods are consistent with the methods suggested by Offermann et al. (2009) and Österle et al. (2011) for the different phases.

	Analysis	Design	Evaluation	Diffusion
General phase description	Problem identification and objective specification; state of the art of problem-solving approaches	Justifiable creation of the artefact (iteratively or in sub-solutions)	Validation of artefact against objectives specified; use artefact to solve problem in suitable context	Diffusion of results among the target groups from science and practice
Thesis-related phase description	Problem-centred research entry; state-of-the-art analysis of patient pathways, pathway methods, network quality, pathway- and indicator modelling; state of the practice survey of pathways in health care networks	Creation of the patient pathway method (comprehensive framework, detailed method design for the patient pathway development phase) incl. quality perspective in conceptual pathway models	Demonstration and validation of (parts of) the patient pathway method in application domain (using the examples of comprehensive cancer care, stroke care)	Communication of problem, its importance, the patient pathway method, its utilities, and rigor of design - especially at IS and healthcare conferences, continuous exploitation in research and development projects
Research methods used	Literature reviews (scoping review, systematic literature review), survey, qualitative data collection with user stories (requirements analysis), qualitative content analysis, expert workshops	Argumentative deductive and argumentative inductive analyses, conceptual modelling, user-centred (requirements-based) method engineering	Expert reviews (continuous feedback loops in interviews, workshops or via mail), assessment of fulfilment of requirements, assessment of expected impact	Scientific papers, conference presentations, university lectures and seminars, funding applications, exploitation of results in project work

Figure 3: Research phases and methods used (based on Peffers et al. (2007), Offermann et al. (2009) and Österle et al. (2011)).

3 Genesis of the Doctoral Thesis

This doctoral thesis is the result of a cumulative research project implementing the research design described in chapter 2. It comprises six scientific research articles (papers P1 to P6), each an independent research work addressing one of the three research objectives and answering particular research questions of this doctoral thesis. The overall structure and the thematic relations between the individual articles are described in section 3.1. Each paper is outlined in the corresponding sections 3.2 to 3.4, describing the context, method and results of the individual papers. The papers' contributions to research and practice are discussed seperately in section 4.1.

3.1 Overall Structure and Context

The six papers P1 to P6 contribute to the overall research objective of this doctoral thesis by answering the research questions raised in section 2.2. They are the results of different phases of the overall DSR research process conducted and apply the corresponding methods as described in section 2.3. The overall structure, context and positioning of the papers along the research phases are depicted in Figure 4. It also indicates which chapters of this doctoral thesis contain the respective full papers. Five of them are published (P1, P3 to P6) in the proceedings of highly ranked IS conferences and one (P2) is submitted for publication as represented in the diffusion phase in Figure 4 (see also Appendix A). Regarding diffusion activities, the importance and motivation together with the results of the research were continuously communicated to target groups in the domains of IS and healthcare research and practice (see also Appedix B). The project contexts of Care4Saxony and iPAAC supported a broad diffusion and communication of research results on a national and European level.

In the papers P1 and P2, the foundations for a uniform understanding of patient pathways are created (addressing research objective RO1 – understanding of patient pathways). In publication P1, the state of the art of patient pathways and how they are addressed in the literature is analysed. Six common themes and the essential descriptive characteristics of patient pathways are identified. In paper P2, these characteristics are validated by developing a questionnaire and applying it in the domain of integrated cancer care. Incorporating the survey results, a definition of patient pathways is proposed. Furthermore, current implementation practices and expected impacts regarding patient pathways are surveyed.

The results of both papers P1 and P2 are used as knowledge inputs for the design of a methodical artefact – the patient pathway method – to support patient pathway development and implementation in the context of integrated care networks with the papers P3 and P4 (addressing research objective RO2 – methodical support for patient pathway development and implementation). Therefore, in publication P3, a general pathway framework is consolidated from the
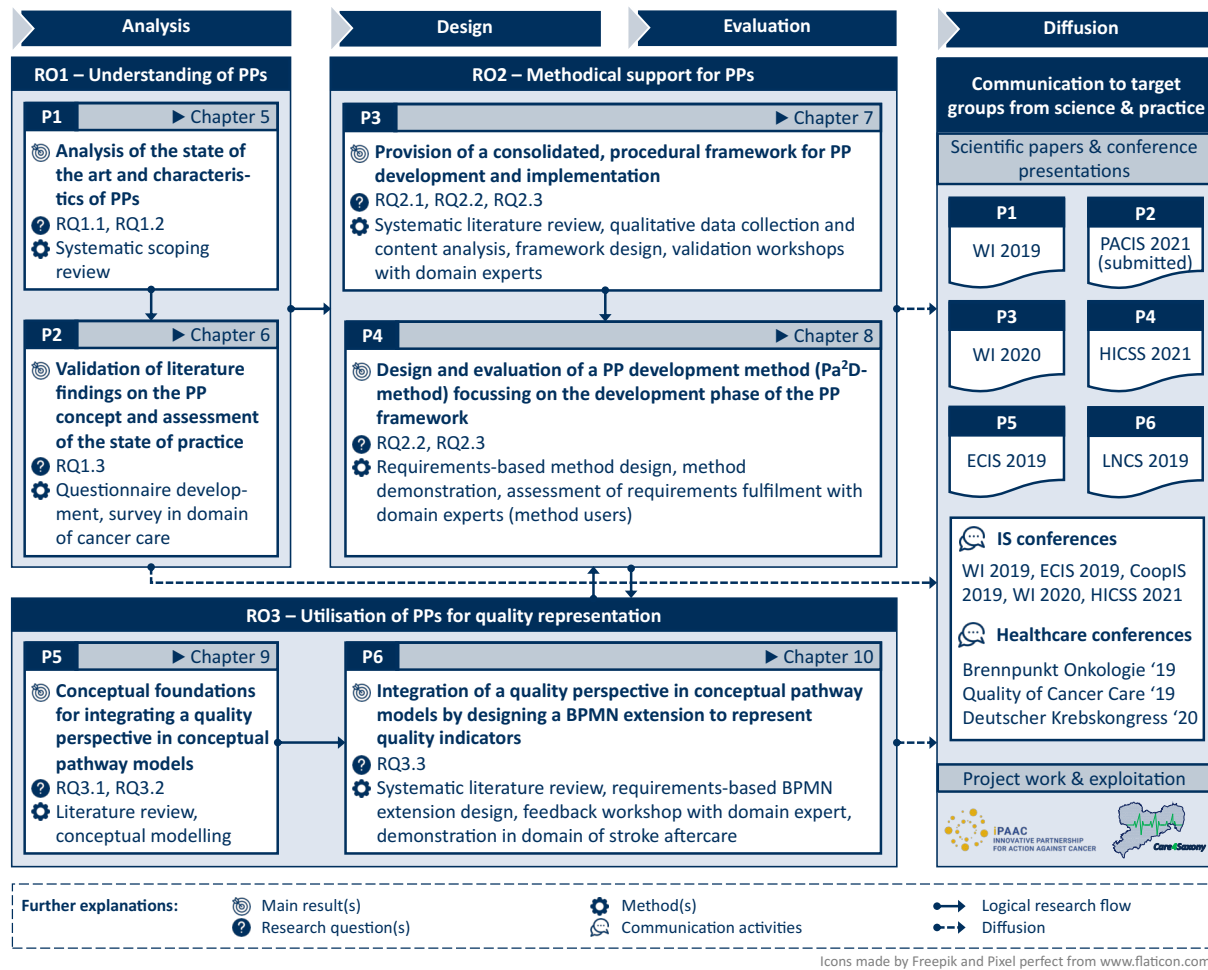
Figure 4: Structure and context of the papers of the doctoral thesis aligned to the research phases.

literature and then extended with additional steps specific for patient pathways. These specifics were identified in workshops with experts in the domain of integrated cancer care. As the result, a procedural framework consisting of eight phases covering the whole lifecycle of patient pathways is presented. The eight phases are (1) screening, (2) project management, (3) diagnostic and objectification, (4) development, (5) implementation, (6) usage, (7) evaluation and (8) continuous follow-up. The focus of the following publication P4 is on practically supporting and detailing the development phase (phase 3 of the consolidated framework) by designing a patient pathway development method (abbreviated with Pa^{2}D-method). It defines a role model and procedural steps of the method. The Pa^{2}D-method is demonstrated with a use case from oncology care and validated by domain experts involved in the development process of the oncological patient pathway.

The procedure of the Pa^{2}D-method includes the definition of evaluation measures, such as quality indicators to be assessed along the pathway. To utilise patient pathways for such quality

management purposes, the publications P5 and P6 concern the integration of a quality perspective in conceptual pathway models (addressing research objective RO3 – utilisation of patient pathways for quality representation). Therefore, paper P5 provides the conceptual foundations by analysing and structuring the realm of process quality by means of a classification framework. Furthermore, a domain ontology, integrating relevant concepts for the representation of quality aspects in pathway models, is elaborated. Building on these preparations and on existing work in the field of conceptual indicator modelling, a BPMN (Business Process Model and Notation) language extension to integrate quality indicators in conceptual pathway models is designed, validated and demonstrated in publication P6. In the following sections, each paper P1 to P6 is outlined and positioned in the context of this doctoral thesis.

3.2 Understanding of Patient Pathways

Both papers P1 and P2 contribute to answering the three research questions RQ1.1, RQ1.2 (P1) and RQ1.3 (P2) to achieve the subordinate research objective RO1 – creating a uniform understanding of the patient pathway term to overcome inconsistency and uncertainty of its use in both science and practice. Thus, both papers contribute to the field of action A (inconsistent understanding and use of the term) as described in section 1.2. The context, methods and results of both papers are outlined in the following.

3.2.1 Outline of P1 – Understanding Patient Pathways in the Context of Integrated Health Care Services: Implications from a Scoping Review

Context and Method

To set the foundations for a uniform comprehension of the term patient pathway, publication P1 (Richter and Schlieter (2019c)) aims at analysing the current literature body available (relating to RQ1.1 – state of the art). The key characteristics of the concept of patient pathways were identified to distinguish them from other well-known pathway approaches, such as clinical pathways or care pathways (relating to RQ1.2 – characterisation). Therefore, a systematic scoping review was conducted in April and May 2018. This review type is used to map key concepts underpinning the research area of patient pathways and thus, to clarify the conceptual understanding of the topic (Anderson et al. (2008), Grant and Booth (2009), Peters et al. (2015)). The final analysis included 132 publications from both scientific and grey literature.

Results

In general, the results of the analysis underline the continuously increasing interest in the topic of patient pathways over time. Furthermore, a great focus of the disease-specific publications

analysed is on patient pathways in cancer care (with more than half of the analysed, disease-specific publications). The literature analysis resulted in six common research themes related to patient pathways. These themes are (1) definition and conceptualisation, (2) development and implementation, (3) analysis of patient pathways, (4) responsibilities and roles, (5) tool and IT-support and (6) simulation. The findings prove the absence of a uniform patient pathway definition consistently applied in the literature. Therefore, key characteristics describing the concept of patient pathways were derived as given in Figure 5.

Patient pathways
- state and align functional, biological and patient-individual **goals of care**.
- focus on patient group and individual patient planning and management, especially for **complex and long-term conditions**.
- describe and sequence the **key care components**, guide the care provision and the patient journey.
- comprise the **whole care journey of a patient (type) -** covering inpatient and outpatient care, which renders them interorganisational pathways.
- are developed, implemented and used by a **multidisciplinary team of professional and informal care providers**, also including the patient him-/herself.
- are typically developed using the latest medical **evidence** but also refer to experts' **experiences** (especially for indication-independent and non-medical parts of the pathway).
- are mainly used for the **purposes** of patient information, documentation, monitoring and evaluation, e.g. care quality and efficiency assessments.

Figure 5: Key characteristics of patient pathways (summarised from paper P1).

These characteristics are discussed in relation to other pathway approaches, especially care pathways and clinical pathways. To sum up this discussion, patient pathways comprise the core concepts of these two approaches but have a stronger focus on the individual patient by incorporating patients' needs and preferences as well as mechanisms for patient involvement and empowerment. Also, patient pathways have a stronger focus on covering the whole continuum of care for patients with complex and long-term health conditions, across all involved health service providers of an integrated care network.

Based on the results, implications for future research and practice are discussed. These include the needs for a consensus regarding the patient pathway understanding as well as for stronger methodical support for patient pathway development and implementation. The former is addressed in paper P2, whereas the latter is in the focus of RO2, covered by the publications P3 and P4.

3.2.2 Outline of P2 – Validating the Concept of Patient Pathways: A European Survey on Their Characteristics, Definition and State of Practice

Context and Method

Taking up the results from publication P1, paper P2 focuses on validating the characteristics of patient pathways identified from the literature by surveying practitioners in the field of integrated care delivery. By matching the state of the art in research and practice, a consensus on a uniform definition shall be facilitated (relating to answering RQ1.3 – assessment and state of the practice). To achieve this, a survey questionnaire was developed and tested. The questionnaire covers three areas of interest which are

1. characteristics of patient pathways (to assess to which extent the survey participants agree with characterising statements derived from the literature on a 5-point Likert scale, see section 3.2.1, Figure 5),

2. definition of patient pathways (to assess the agreement on a proposed definition and suggestions for improvement) and

3. patient pathway practice (e. g. experiences with patient pathways, representation formats, patient pathway usage and potentials).

The questionnaire was pre-tested with experts in the domain of cancer care from Luxembourg (National Cancer Institute) and Germany (German Cancer Society). The final version (see Appendix C) was provided online and answered completely by 19 members of the patient pathway working group involved in the iPAAC project. The survey participants comprised experts from practical cancer care, research, cancer network management and certification, national health ministries, European and national cancer organisations and patient organisations.

At the time of submitting the doctoral thesis, paper P2 is submitted for publication at the Pacific Asia Conference on Information Systems 2021. An abstract of the results in the domain of cancer care has already been published and presented at the Quality of Cancer Care congress in 2019 (Richter and Schlieter (2019a)).

Results

The answers to the first part of the patient pathway questionnaire show a broad acceptance of the patient pathway characteristics identified from the literature. For example, the survey participants confirm the assumption that patient pathways should especially consider disease-related and organisational goals of care as well as planning and management of individual patients and patient groups. Interestingly, a strong patient engagement in patient pathway development and decision-making raises a few critical voices among the participants.

Based on the literature findings presented in publication P1, an initial definition of patient pathways was proposed to the survey participants in the second part of the questionnaire. They were asked if their understanding is represented by this definition of patient pathways and if they had suggestions for improvement. The proposed definition is broadly supported by 89% of the respondents. After slightly revising it in terms of the improvements proposed, the following definition is recommended to be used in further patient pathway studies:

> *A **patient pathway** is an evidence-based 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. It 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 his/her multidisciplinary care team collaborating in a comprehensive network of care providers.*

The third part of the questionnaire addresses patient pathway practice. It is shown that there is no uniform standard established for the representation of patient pathways in practice. However, conceptual process models are most commonly used in comparison to prosaic descriptions, checklists or table forms. In terms of practical benefits to be expected with the implementation and usage of patient pathways in CCCNs, the survey participants agreed that improved care coordination and quality of care are the main advantages. Additionally, patient pathways are expected to have potential for increasing care standardisation, compliance with standards and patient satisfaction.

3.3 Methodical Support for Patient Pathway Development and Implementation

As argued with the field of action B (insufficient implementation and comparability of patient pathways) in section 1.2 and as shown by the results of the papers P1 and P2, comprehensive methodical support for the development and implementation of patient pathways in integrated care networks is insufficient (relating to research objective RO2 – methodical support for development and implementation). In the publications P3 and P4, this gap is addressed by designing a patient pathway method (as core DSR design artefact of this doctoral thesis) by applying a user-centred, requirements-based approach. It uses a patient pathway template approach that allows developing and implementing evidence-based patient pathway templates. Functioning as generic design patterns to be adapted to the individual conditions and environments of specific integrated care networks, this approach contributes to better comparability of patient pathways. The knowledge created on the understanding and definition of patient pathways as well as on current practice and expectations (relating to research objective RO1 – understanding of patient

pathways – and documented with the papers P1 and P2) is used as foundational input for the development of this method.

3.3.1 Outline of P3 – Paving the Way for Patient Pathways: Synthesizing a User-Centered Method Design with Results from a Systematic Literature Review

Context and Method

The objective of paper P3 (Richter and Schlieter (2020)) is to support the development and implementation procedure of patient pathways in integrated care networks. It contributes to answering the three research questions RQ2.1 to RQ2.3. To avoid creating a patient pathway method from scratch, existing methodical work on pathways in general was collected and analysed by means of a systematic literature review. This resulted in a consolidated pathway framework. With the results of workshops with experts in the domain of integrated cancer care, this framework was complemented by additional steps specific for patient pathways. Also, prospective user groups were identified. Therefore, qualitative content analyses of user stories and continuous feedback workshops with the domain experts were applied. The complete list of user stories collected is provided in Appendix D.

Results

With the systematic literature review conducted, nine existing procedural descriptions in the realm of pathway development and implementation were identified. The approach of Vanhaecht et al. (2012) was found to be the most comprehensive and profound one to date. For this reason, it was used as the basis to map the others, resulting in a consolidated pathway framework. Referring to research question RQ2.1 – consolidation of existing approaches – the consolidated framework integrates existing work on general pathway development and implementation issues, independent of specific pathway concepts such as care-, clinical-, or patient pathways. It is applicable for patient pathways since it comprises essential tasks for intra- and interorganisational settings. However, existing work does not cover all aspects specific to patient pathway. Especially, patient engagement and the network governance issues are insufficiently addressed. Furthermore, practical guidance and tool support are lacking. This particularly applies for the development phase.

The prospective user groups of an intended methodical patient pathway support (referring to research question RQ2.2 – design requirements) were identified to be the following: (1) care units of integrated care networks, such as physicians, nurses, personnel in training, network (quality/process) managers, network advisors, (2) national and international health care organisations, (3) policy representatives, e. g. national health ministries, national and international
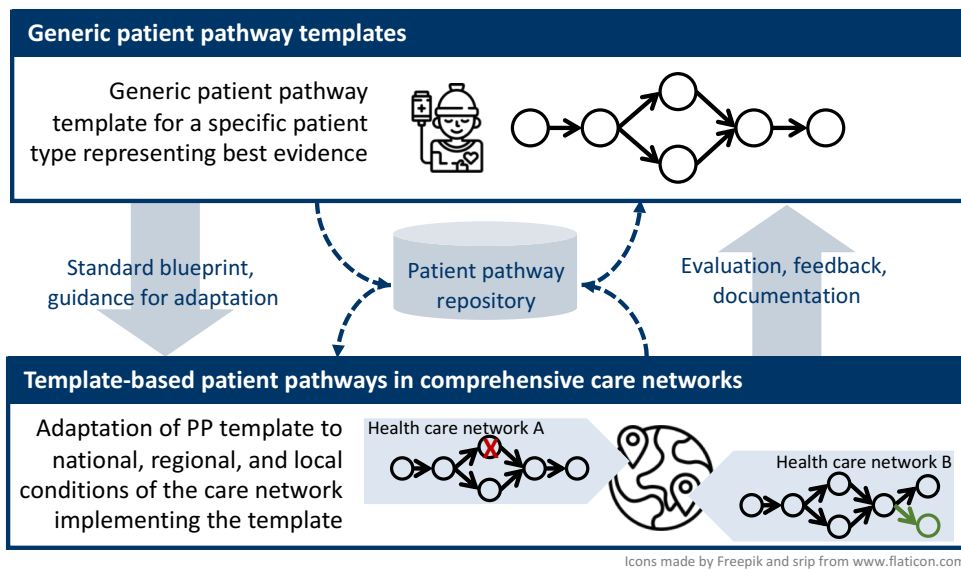
Figure 6: The template-based patient pathway approach.

health policy developers or advisors, (4) patients and patient representatives, (5) researchers, (6) technical experts and (7) methodologists, e. g. for pathways or medical guidelines. The first three were agreed to be the main user groups.

With the qualitative analysis of the user stories collected and the results of the expert workshops, 17 additional user requirements specific for patient pathways were identified. They especially cover the missing aspects of network governance and patient engagement. Complementing and expanding the initial literature-based pathway framework, the final procedural patient pathway framework consists of eight phases covering the whole lifecycle of patient pathways. These phases are (1) screening, (2) project management, (3) analysis and evaluation preparation (diagnostic and objectification), (4) development, (5) implementation, (6) usage, (7) evaluation and (8) continuous follow-up. In publication P3, practical steps for each phase are described.

The emphasis of developing generic patient pathway templates and adapting them to national, regional and local conditions of integrated care networks turned out to be a key user requirement and the main distinguishing and innovative feature of the new procedural patient pathway framework. Patient pathway templates for specific patient types of complex, long-term diseases shall function as guiding blueprints for the development of patient pathways in integrated care networks. The templates shall describe and structure the phases and steps of care for such patient types along the whole continuum of care in such networks. They shall guide the development of network-specific patient pathways by adapting the template to national, regional and local conditions of this network (see Figure 6 for illustration). This template-based patient pathway approach is expected to support network governance. Quality of care across different care networks shall be increased by enabling better comparability, consistency and uniformity

Phase		Purpose	Main Steps
Preparation	Screening	To gain an overview of the current environment and evidence.	• Identify need for and appropriateness of PP template • Analyse environment (evidence, domain, setting) • Check for existing PP templates and good practice examples
	Project Management	To define the PP template project aim and to set up the project.	• Define clinical question • Establish multidisciplinary PP template development team • Set up project plan • Train and educate team on PP template initiative and project plan
	Analysis & Evaluation Preparation	To evaluate current evidence and care process. To prepare evaluation of PP implementation.	• Analyse current organisation of the care process from four perspectives: network and team, patient and family, available evidence and legislation, external partners • Define process and outcome indicators
Development & Utilisation	Development	To design and approve a disease-specific PP template.	• Select PP template representation format • Draft PP template • Review template draft, consensus finding, refinement, approval • Template documentation to guide its implementation
	Implemen-tation	To evaluate PP template design, value and usability in pilot network. To refine and approve PP template.	• Set up implementation plan • Post pilot refinement of PP • Inform and train template users template • Pilot PP template in comprehen- • Develop messaging and sive care network dissemination strategy
	Usage	Provide PP template to enable its usage. Implement updates.	• Make tested and agreed PP templates available in PP template repository • Revise and update PP template if necessary (based on results of continuous follow-up)
Improvement	Evaluation	To assess and communicate the improvements made by PP template provision.	• Evaluate usability and defined indicators • Communicate evaluation results • Adjust PP template if necessary • Add PP template and evaluation documents to repository
	Continuous Follow-up	To monitor PP template usage, deviations and recognise necessity for refinement.	• Define responsibilities for continuous monitoring • Check relevance of PP template at fixed time intervals • Continuously evaluate PP template using adaptation feedback

Icons made by Freepik, geotatah, Kiranshastry, Eucalyp, and Iconnice from www.flaticon.com

Figure 7: Development of generic patient pathway templates according to the eight phases of the procedural patient pathway framework.

of care provision. The expected impact of the template-based approach is elaborated on in more detail in section 3.3.3.

This template-based approach leads to the distinction of three perspectives of the procedural patient pathway framework. These are

- the development of generic patient pathway templates for a specific patient type but independent of specific care networks,

- the development of patient pathways for a specific care network using an approved generic patient pathway template and

- the development of patient pathways from scratch in case there is no template available.

Depending on the perspective, some of the necessary steps along the eight phases of the framework differ. To illustrate this, the purpose of each phase and the main steps for the perspective of developing generic patient pathway templates are summarised in Figure 7. In publication P3, a table representing the comprehensive, procedural patient pathway framework and

distinguishing between the three perspectives is given. This framework provides guidance for designing a patient pathway method (referring to research question RQ2.3 – method design).

3.3.2 Outline of P4 – Patient Pathways for Comprehensive Care Networks – A Development Method and Lessons from its Application in Oncology Care

Context and Method

The development of patient pathways and templates (phase four of the consolidated patient pathway framework) is not sufficiently supported in terms of comprehensive, practical guidance as identified by the analysis of publication P3. To close this gap, a patient pathway development method (Pa^{2}D-method) is designed in publication P4 (Richter and Schlieter (2021)). For its development, a requirements analysis based on user stories (see Appendix D) was performed. Hence, publication P4 focusses on answering the research questions RQ2.2 – design requirements – and RQ2.3 – method design – of this doctoral thesis. The main phases of the Pa^{2}D-method (see Figure 8) are in line with the content of the consolidated patient pathway framework of publication P3, yet broken down to the essentials of the template-based approach.
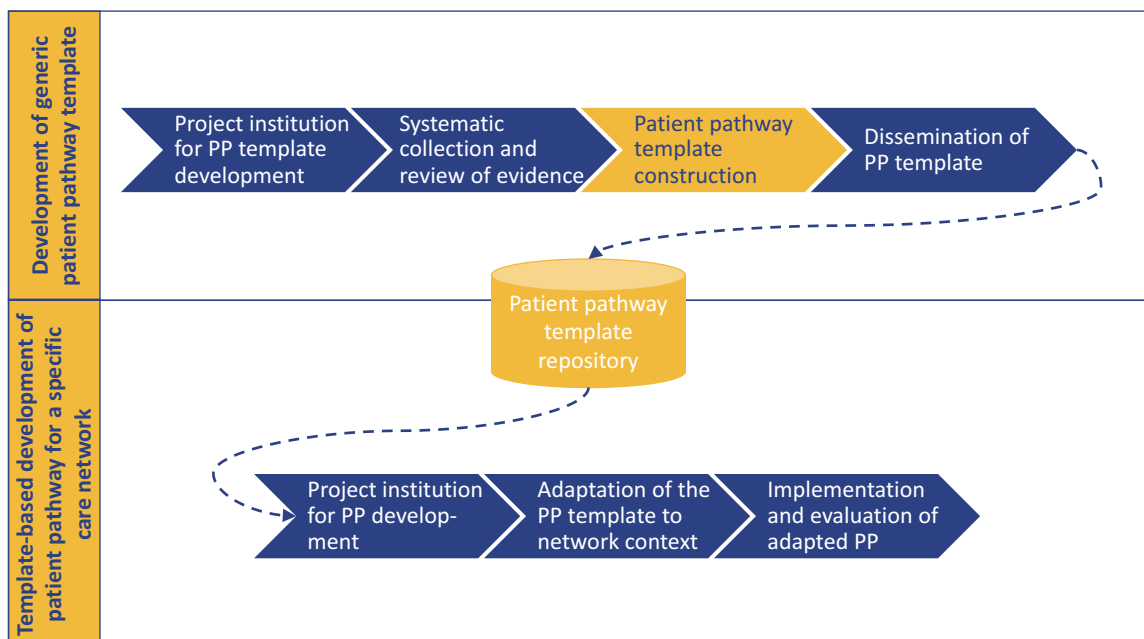
Figure 8: Main phases of the Pa^{2}D-method (adapted from paper P4).

The Pa^{2}D-method covers both the development of generic patient pathway templates and the template-based development of patient pathways for specific care networks. The template construction, however, is the focal point of the method description in paper P4. The Pa^{2}D-method was demonstrated with a use case from oncology care and validated by the working group participants involved in the development process of the examplary oncological patient pathway

template. Therefore, a questionnaire surveying the experiences with the method application and the degree of fulfilment of requirements was provided (see Appendix E). Six completed questionnaires were received and analysed.

Results

Prior to the method design, functional and non-functional requirements were derived from user stories formulated by domain experts in the field of integrated care delivery. In summary, the following seven functional requirements R1 to R7 were identified (Richter and Schlieter (2021)), answering research question RQ2.2 – design requirements.

- **R1.** Patient pathways should have uniform template character and provide adaptation notes for their implementation to particular integrated care networks.

- **R2.** Patient pathways should be disease-specific.

- **R3.** Patient pathways should be developed by a multi-stakeholder working group.

- **R4.** A patient pathway development method should define the group processes.

- **R5.** Patient pathways should be developed based on scientific evidence, especially medical guideline recommendations. The link of the patient pathway content to its evidence base should be maintained.

- **R6.** A patient pathway should sequence obligatory and optional steps and the relevant information along all phases of care for the involved care providers and the patients in an integrated care network.

- **R7.** Patient pathways should provide a patient view to support shared decision-making and individualisation.

These requirements were used to design the Pa^{2}D-method. It consists of a role model and the description of procedural steps including corresponding process inputs and outputs. Figure 9 illustrates the roles defined, the procedure to construct a patient pathway template and how the method is integrated in the framework presented in publication P3 (answering research question RQ2.3 – method design). This is described in detail in publication P4.

The method is demonstrated and assessed in the domain of integrated cancer care in the context of the iPAAC project. A patient pathway template for colorectal cancer care in CCCNs was developed together with a working group consisting of interdisciplinary and international patient pathway template stakeholders and users, template designers and method experts. The procedure of the Pa^{2}D-method, especially the template construction and the output (the colorectal cancer patient pathway) were assessed in terms of fulfilment of the defined requirements R1
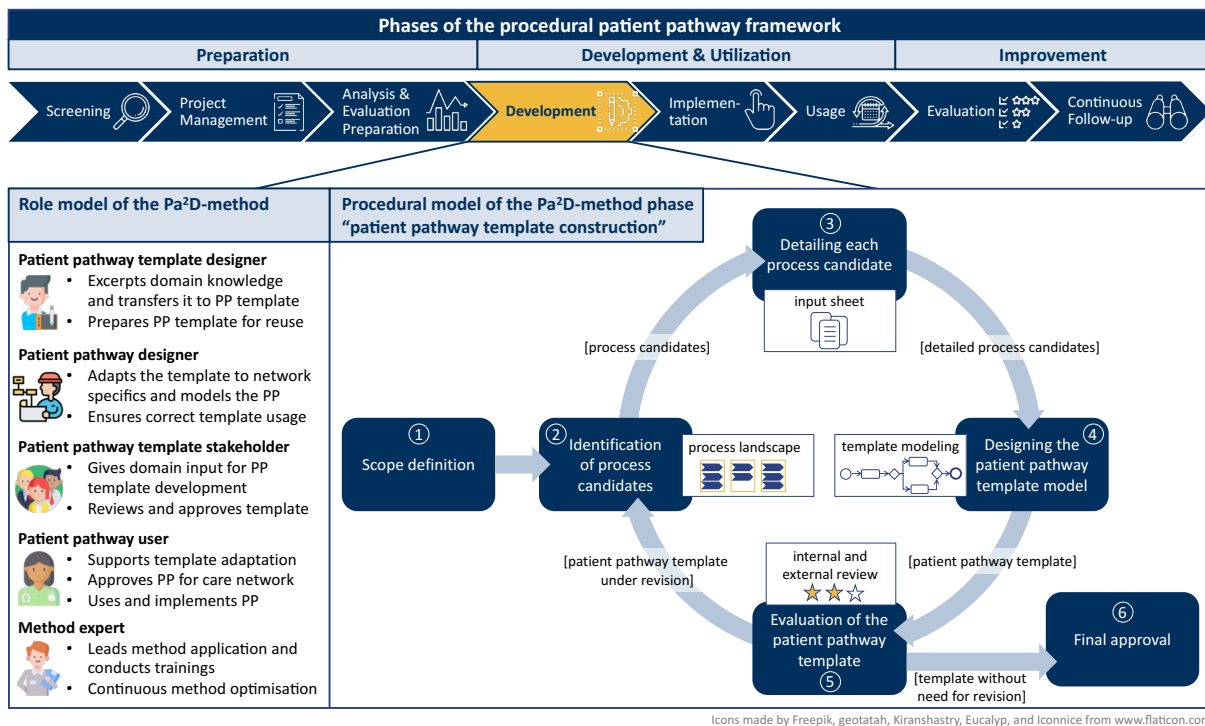
Figure 9: Role model and construction procedure for patient pathway templates according to the Pa²D-method (summarised from paper P4).

to R7. Overall, the assessment by the working group participants is positive. Mostly, strong agreement that the requirements are well implemented by the Pa²D-method is shown. However, the assessment results regarding requirements R4 and R5 indicate potential for improvement of the method. Lessons learned from the experiences with the use case from oncology care and the assessment results are described in detail in publication P4. The extent of requirements fulfilment is argued as follows (Richter and Schlieter (2021)).

- **Assessment of R1.** The template development and its implementation are seperated (template-based development of a patient pathway for a specific integrated care network). The template construction is specified as main phase of the Pa²D-method.

- **Assessment of R2.** A patient pathway template is developed for a specific disease, specified by in- and exclusion criteria in the scope definition of the template construction.

- **Assessment of R3.** An interdisciplinary multistakeholder group is defined by the role model of the Pa²D-method. It covers different professions and knowledge domains of all stages of care along the patient pathway and the care network's units.

- **Assessment of R4.** The group composition and consensus finding process are to be defined during the project institution phase of patient pathway template development. As

potential for improvement of the Pa^{2}D-method, a stronger guidance to define the group processes, e. g. the consensus finding process, was identified.

- **Assessment of R5.** The systematic collection of evidence is defined as separate phase. For patient pathway template construction, the current evidence base is used. The method recommends modeling languages which provide concepts for the representation of evidence in conceptual patient pathway models. As potential for improvement of the Pa^{2}D-method, an even stronger integration of the evidence base was identified.

- **Assessment of R6.** Obligatory and optional concepts are defined with annotations in the conceptual patient pathway template model. Adaptation notes are described.

- **Assessment of R7.** Patient representatives are explicitly included as patient pathway template stakeholders. A patient view with specific tasks to be performed by the patient him-/ herself is included in a patient pathway template.

Following the procedural patient pathway framework (see paper P3, section 3.3.1), implementing the template by pilot testing it in selected care networks shall be the next step. Thereby, bottlenecks and potentials for further improvement of the Pa^{2}D-method can be identified.

3.3.3 Assessment of the Template-Based Patient Pathway Approach

The template-based patient pathway approach implements reference modelling, as already argued in paper P4. Patient pathway templates function as guiding blueprints for the development of network-specific patient pathways (see description in section 3.3.2). According to vom Brocke (2015), a reference model is developed or used to support the construction of application models, with the relationship between the reference model and the application model being characterised by the fact that the object or content of the reference model is reused in the construction of the object or content of the application model. Thus, a patient pathway template can be referred to as a reference model and the patient pathway constructed reusing the template as application model.

Through reuse, both effectiveness and efficiency in modelling and IS development are aimed to be increased (Kirchmer (2009)). Similar to typical advantages of reference modelling (Fettke and Loos (2007)), the template-based patient pathway approach has the potential to increase safety for patients and health service providers, to reduce risks and costs during pathway development (e. g. by shortened development time) and to increase pathway quality. Such impacts are to be measured and benefits need to be shown to establish the development and implementation of patient pathway templates as standard for health care network governance.

To take a first step in the direction of evaluating the template-based patient pathway approach, a preliminary study on the impacts expected was conducted. Therefore, a survey to assess the
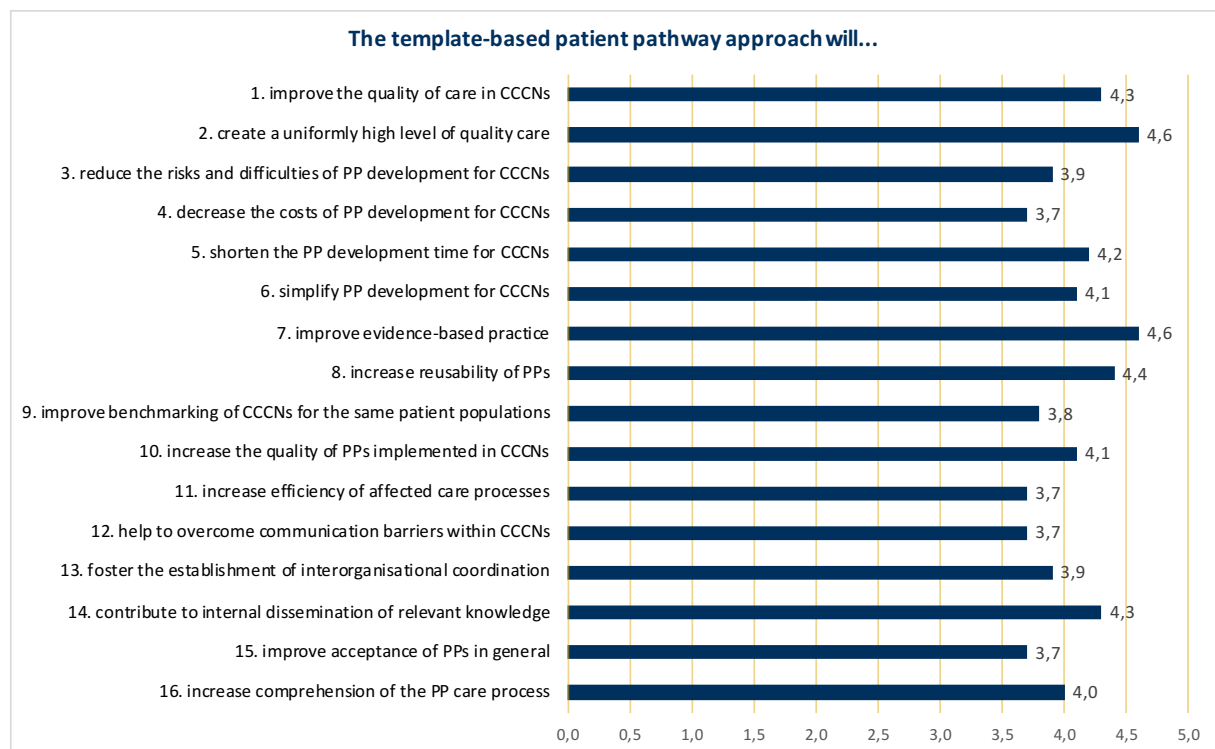
Figure 10: Results of the preliminary study on the expected impact of the template-based patient pathway approach (n = 20 for items 1 to 8, n = 18 for items 9 to 16).

impact of the approach in the context of integrated cancer care was carried out. Altogether, the survey consisted of 16 items, which were mainly selected from the conceptual evaluation framework proposed by Frank (2007b) and adapted to the pathway context. The focus was on items from the economic perspective of the framework since the survey aimed at providing only initial insights into which impacts could be expected and investigated further. Specific expectations indicated in the patient pathway literature (e. g. Albreht et al. (2017)) were also included as items in the survey.

The survey was conducted with the partners of the iPAAC project. They were asked to assess the impact of the template-based patient pathway approach in the context of CCCNs on a 5-point-Likert scale. The participants were familiar with the approach studied since they were involved in the development of the patient pathway method and the patient pathway templates for pancreatic and colorectal cancer. The survey was carried out in an online project meeting in November 2020. In sum, 20 answers were collected for the items 1 to 8 and 18 answers were collected for the items 9 to 16. The results are presented in Figure 10.

Reflecting on these results, the provision of patient pathway templates and their implementation by adapting them to national, regional and local specifics of CCCNs seems to be a promising approach. The greatest impact of such templates is expected to be an increase of quality and standardisation (uniformity) of care across different care networks. Also, since patient pathway

templates implement the recommendations from clinical practice guidelines, they are expected to generally improve evidence-based practice. Furthermore, the results of the survey indicate that the reusability of pathway templates is another important benefit. It is expected to reduce costs and time during the development process. The development of patient pathways is also expected to become simpler and to result in a better quality of patient pathways implemented in CCCNs.

3.4 Utilisation of Patient Pathways for Quality Representation

As argued with the field of action C (lack of linkage to quality specifications) in section 1.2, there is no sufficient methodical support for the utilisation of patient pathways for quality management purposes. Therefore, the preparation phase of the procedural patient pathway framework as described in publication P3 (see section 3.3.1) already addresses the definition of process and outcome indicators. Furthermore, the procedure of the Pa^{2}D-method includes the definition of evaluation measures such as quality indicators to be assessed along the pathway (publication P4, see section 3.3.2). To stronger support the utilisation of patient pathways for quality management purposes (addressing research objective RO3 – utilisation for quality representation), paper P5 provides the conceptual foundations for the development of a BPMN language extension to integrate a quality perspective in conceptual patient pathway models presented in paper P6. The solution provided is applicable not only to patient pathways but to pathways in health care in general (i. e. also to similar pathway approaches such as clinical pathways or care pathways). The BPMN extension adds a practical tool to the patient pathway method described in section 3.3. With this extension, the utilisation of patient pathways for quality management purposes is supported.

3.4.1 Outline of P5 – Bringing Care Quality to Life: Towards Quality Indicator-Driven Pathway Modelling for Integrated Care Networks

Context and Method

In publication P5 (Richter (2019)), the integration of a quality perspective in conceptual pathway models is prepared. Therefore, the realm of process quality in integrated care is analysed and structured by means of a classification framework (addressing research question RQ3.1 – quality classification). Moreover, relevant concepts for the integration of quality indicators in care pathways are analysed and represented with a semi-formal domain ontology (referring to answering research question RQ3.2 – conceptual integration). To achieve this, a literature review on process-related quality indicators in health care was conducted and conceptual domain modelling was applied.
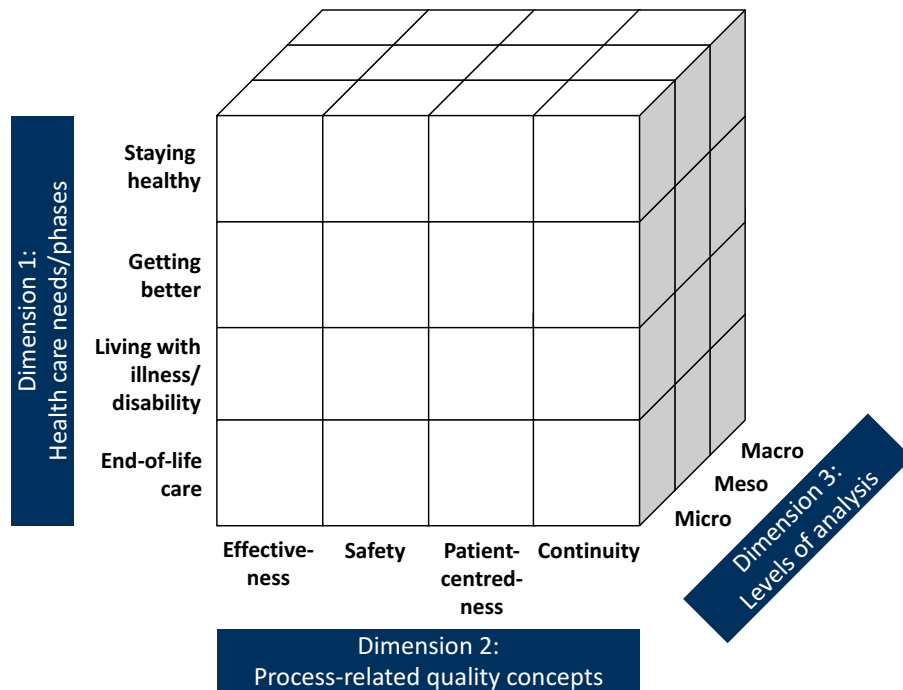
Figure 11: Classification framework for process quality in integrated care settings (paper P5).

Results

Using the results of the literature review conducted, a classification framwork for process-related quality measures in integrated care networks was developed (see Figure 11). It comprises three dimensions and is partly based on the conceptual framework for the OECD Health Care Quality Indicators Project (Arah et al. (2006)). It was modified according to this thesis' research objective by adapting the dimension of process quality to better fit integrated care settings and by extending the original matrix by a third dimension (the level of analysis). Dimension 1 focusses on the phases of integrated care delivery, covering the whole continuum of potential health care needs of a person – from staying healthy, getting better, living with an illness or disability to end-of-life care. Therewith, all typical phases of a patient pathway are covered. In dimension 2, process-relevant quality aspects in integrated care settings are classified into four major realms. These are effectiveness, safety, patient-centredness and continuity. In dimension 3, quality indicators are classified according to the level of analysis used for quality measurement, i. e. micro-, meso- and macro-levels.

Bearing in mind the overall aim of integrating a quality perspective in conceptual pathway models, a semi-formal domain ontology integrating all relevant concepts was developed. It helps gaining a comprehensive understanding of the domain (pathway-based quality modelling), its concepts, attributes and their relations (Happel and Seedorf (2006), Uschold (1996)). The domain ontology developed is structured into four areas covering the relevant concepts related

to the patient, the pathway, the care provider and the process quality. The three dimensions of the classification framework were integrated as individual concepts in the domain ontology. The ontology was used and further modified as part of the domain analysis when conducting the extension procedure to develop a BPMN extension to integrate a quality perspective in patient pathway models. Thus, it is incorporated in the final domain ontology prepared for the pathway extension as depicted in Figure 12 related to publication P6.

3.4.2 Outline of P6 – Process-Based Quality Management in Care: Adding a Quality Perspective to Pathway Modelling

Context and Method

Building on the conceptual groundwork presented in paper P5, publication P6 (Richter and Schlieter (2019b)) provides a systematically developed BPMN extension to integrate a quality perspective, i. e. quality indicators, in conceptual pathway models (addressing research question RQ3.3 – quality modelling in pathways). A systematic literature review on (quality) indicator modelling complements the findings of paper P5. The systematic review extends the review on performance indicator modelling conducted by Livieri et al. (2015) by adding search terms related to quality management and health care. With the database search and screening of results, 14 relevant scientific contributions were identified. They were analysed regarding indicators they focus on as well as how they address an integration of indicators in process- or pathway models. The findings set the foundation for a comprehensive domain requirements analysis as part of the BPMN extension procedure described by Braun and Schlieter (2014) and applied for the purpose of paper P6. Overall, the BPMN extension shall support managers, health service providers as well as patients in better exploiting the potentials of patient pathways as a quality management tool.

Results

The literature review conducted did not result in works specifically focussing on modelling quality indicators. Instead, existing work to date is on business goal modelling and the modelling of process- and organisational performance indicators. The approaches identified were used for the own conceptualisation and representation of quality indicators in pathway models since they share similar concepts.

The domain analysis also includes the definition of user-related requirements for the integration of a quality perspective in pathway models (e. g. quality indicators represented at the relevant reference point in the pathway, representation of the source of a quality indicator, representation of relevant attributes of a quality indicator). The requirements were reviewed and
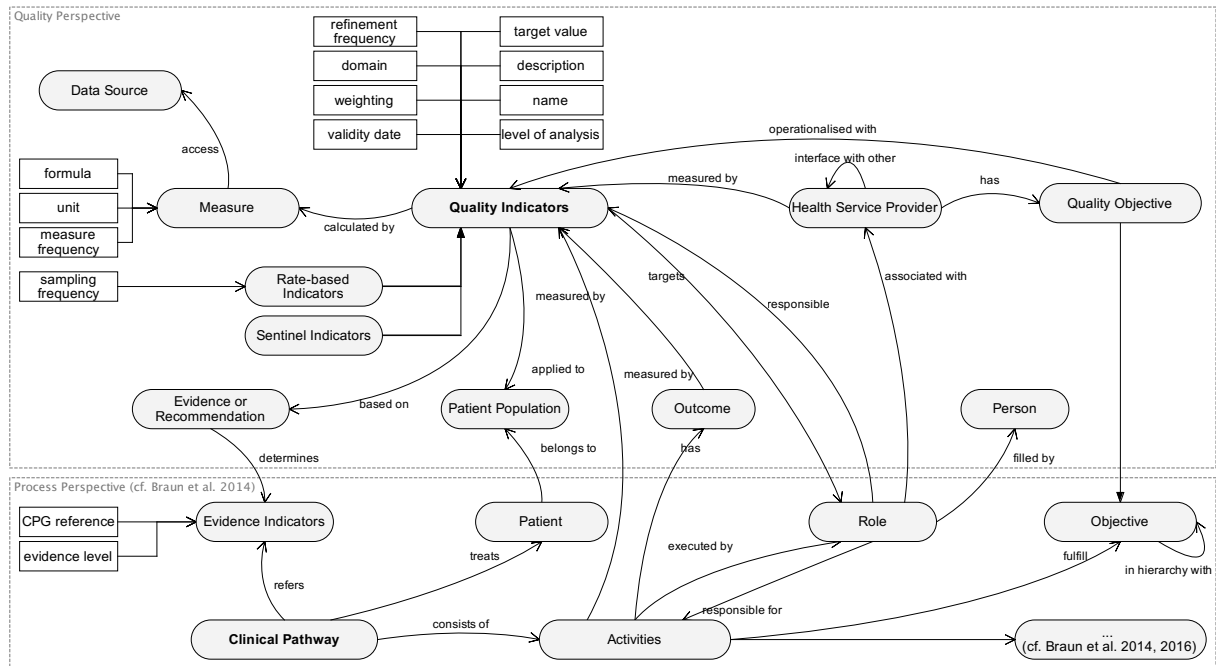
Figure 12: Domain ontology to extend pathways with a quality perspective, based on the ontology presented by Braun et al. (2014) (paper P6).

revised in a workshop with an expert experienced in quality management and certification of cancer centres on a national and international level.

These requirements, the identified indicator ontologies as well as the preliminary work on the conceptualisation of quality in health care (paper P5, see section 3.4.1) were used to develop the domain ontology represented in Figure 12. Based on this, relevant concepts for the BPMN language extension were identified. Then, the equivalence of these necessary new language elements with existing ones of the standard BPMN and an existing BPMN extension for clinical pathways called BPMN4CP (Braun et al. (2014), revised in Braun et al. (2016)) was checked. Accordingly, the Conceptual Domain Model of the Extension (CDME), functioning as the foundation for the extension of the BPMN meta model, is presented in publication P6. Also, the concrete syntax (graphical representation of the extension in a pathway model) is outlined.

The BPMN extension developed is demonstrated by an example from stroke care. Therefore, a high-level process of acute stroke care, quality objectives and four corresponding quality indicators (QI1.1, QI1.2, QI2.1 and QI3.1) were described and represented. Insights into the application domain of stroke care were gained by an interview with an experienced stroke case manager. In Figure 13, the specification of the quality indicators, their relation to elements in the pathway model as well as the connection to the quality objectives are represented using the BPMN4CP extensions. A separat diagram view ensures that the pathway model is not overloaded with quality information. In paper P6, the demonstration case is described in more detail.
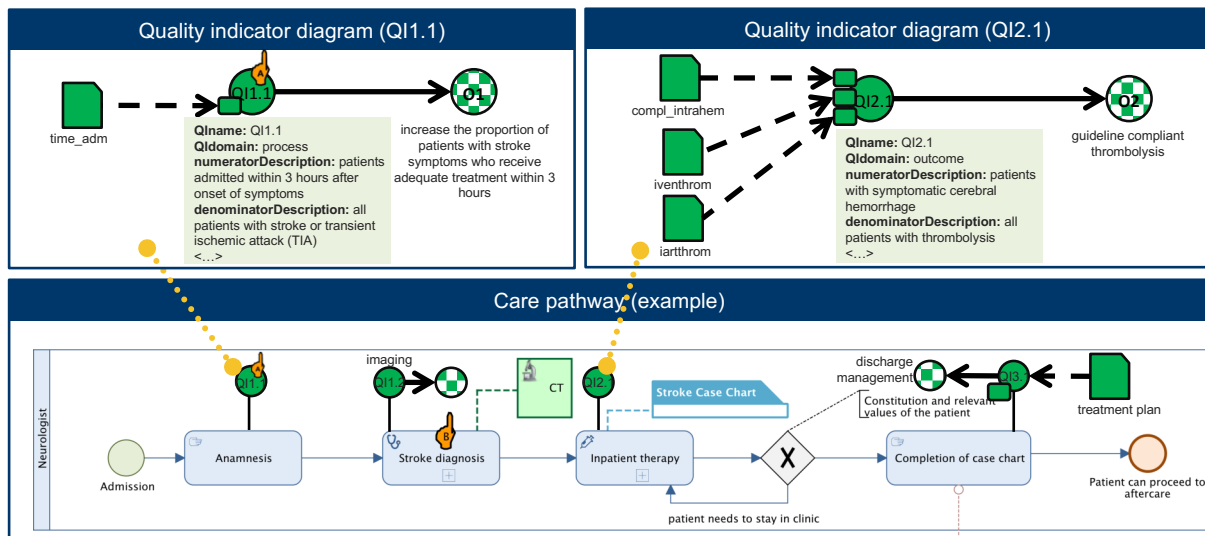
Figure 13: Demonstration of integrating quality indicators in pathway models using the extended BPMN4CP (paper P6).

4 Conclusion

The research conducted describes an in-depth investigation into the understanding of patient pathways (see RO1), methodical support for their development and implementation (see RO2) as well as their utilisation for quality management in integrated care settings by representing quality specifications (see RO3). The contributions of this doctoral thesis to research and practice in these three areas of interest are described in section 4.1. Section 4.2 concludes the work with a critical discussion and an outlook on future research topics.

4.1 Contributions to Research and Practice

Since the three subordinate research objectives of this doctoral thesis are both comprehension and design objectives with methodical focus (see also section 2.2), the main contributions can be specified accordingly. They cover the comprehension objective by providing a characterisation and definition as well as a consolidation of the state of the art and practice of patient pathways. Thus, the work contributes to the understanding of methods and techniques for IS design with integrated care networks being the IS of interest. Furthermore, the results of this thesis provide methodical support for patient pathways in terms of a patient pathway method and a technique to integrate a quality perspective to utilise them for quality management. This contributes to the method spectrum of IS research. At the same time, the application potential of IS methods and techniques, especially of conceptual modelling in the domain of healthcare, is shown. The main contributions of this thesis to both research and practice are summarised in Table 2.

The work contributes to solving problems in the field of action A, i.e. the inconsistent understanding and use of the patient pathway term. Of equal relevance for research and practice are the characterisation and the normative definition of the term patient pathway (Contribution Con-1) provided with the papers P1 and P2. They are beneficial for a uniform understanding of this concept and for a clear distinction from other pathway approaches. They contribute to the knowledge base on pathway terminology. The clarification of the concept supports unravelling the term clutter existing due to many similar pathway terms and concepts for both research and practice. The results highlight patient pathways as an independent concept, help finding a consensus on the term (in both science and practice), and thus, with the creation of a uniform point of reference (Con-15). Furthermore, the consolidation of the current state of the art (Con-12) defines the thematic scope in the literature and identifies issues for future research. The thesis also contributes an analysis of the state of practice by providing and testing a patient pathway questionnaire (Con-9) which can be applied to gain knowledge in other healthcare domains outside the field of integrated cancer care. In summary, the research questions RQ1.1 to RQ1.3 are answered and the corresponding research objective RO1 (understanding of patient pathways) can be considered achieved.

Table 2: Main contributions of the doctoral thesis to research and practice.

Contributions to research and practice
Con-1. Characterisation and normative definition of patient pathways
Con-2. Template-based patient pathway method (guided with the consolidated patient pathway framework and specified with the Pa^{2}D-method)
Con-3. Procedural model and role model for the development of generic patient pathway templates and their implementation provided with the Pa^{2}D-method
Con-4. Classification framework for process quality in integrated care settings
Con-5. Modelling language extension for the representation of a quality perspective in patient pathways
Con-6. Application demonstration

Contributions to research	Contributions to practice
Con-7. Requirements analysis for a patient pathway development method	**Con-13.** Practical guidance for patient pathway development and implementation
Con-8. Requirements analysis for quality representation in patient pathways	**Con-14.** Supporting pathway-based quality management
Con-9. Tested patient pathway questionnaire	**Con-15.** Driving standardisation of patient pathway understanding and development
Con-10. Extension of IS method spectrum	
Con-11. Conception of BPMN extension	
Con-12. Consolidation of current knowledge on patient pathways, their development and on indicator modelling	

The work of this thesis further contributes to the field of action B, i. e. the insufficient implementation and comparability of patient pathways. The core contribution of the publications P3 and P4 is the main design artefact of this doctoral thesis, i. e. the patient pathway method (Con-2). It is framed by the consolidated procedural patient pathway framework covering all necessary phases for patient pathway development, implementation and continuous improvement by evaluation (Con-12). The method uses a template-based patient pathway approach, contributing to standardising the development and implementation of patient pathways and to making them more comparable (Con-15). The comprehensive requirements analysis enables the assessment of the research results and provides evaluation criteria for similar research artefacts (Con-7). Further, the Pa^{2}D-method gives applicable role descriptions and procedural guidance for the construction of patient pathway templates (Con-3). This provides a detailed description of the development phase of the consolidated patient pathway framework. The Pa^{2}D-method was applied by developing colorectal and pancreatic cancer patient pathway templates (Con-6)

to be implemented in European CCCNs (promoted by the iPAAC project). They are to be tested in two pilot networks in Germany and Poland. With the template-based approach of the patient pathway method, a large-scale application of patient pathways in practice can be achieved. This is supported by the results of the preliminary study on the expected practical impacts of this approach (see section 3.3.3). The template-based approach contributes to central network governance. It can be applied by governmental authorities or other regulating bodies, e. g. national or international non-profit care organisations, to improve patient care based on comparable care processes of uniformly high quality across different care networks for the same patient type. For example, as integral parts of medical guidelines, pathway templates could contribute to the implementation of guideline recommendations into care practice and to the evaluation of their application. Given these results in the realm of research objective RO2 (methodical support for development and implementation) the corresponding research questions RQ2.1 to RQ2.3 are answered and the objective can be regarded as achieved.

Finally, this findings of this doctoral thesis contribute solutions to the field of action C, i. e. the lack of linkage between patient pathways and quality specifications, with the publications P5 and P6. Their main contributions for both research and practice are the classification framework for process quality in integrated care settings (Con-4) and the modelling language extension to represent a quality perspective in patient pathways (Con-5, Con-11). This further contributes to the IS method spectrum (Con-10). Also, a consolidation of the current knowledge on indicator modelling is provided (Con-12). The requirements analysis for a representation of a quality perspective in pathway models can be used to evaluate the own language extension and provides criteria for the evaluation of similar approaches (Con-8). From a practical perspective, the results of the papers P5 and P6 support the implementation of a pathway-based quality management (Con-14). In conclusion, the research questions RQ3.1 to RQ3.3 are answered and research objective RO3 (utilisation for quality representation) can be considered achieved.

4.2 Discussion and Outlook

The main design artefact of this doctoral thesis – the patient pathway method including the practical support for quality representation in pathway models – fulfils the four requirements of DOIS research artefacts, i. e. abstraction, originality, justification and benefit (Österle et al. (2011), see section 2.3). The method is generally applicable to integrated health care networks providing care for patients with complex, long-term conditions and not restricted to specific patient types (principle of abstraction). Still, it is indisputable that the domain of cancer care functions as primary use case for the method development, demonstration and assessment (esp. for the requirements analyses, feedback workshops and demonstration cases), complementing the knowledge base used from scientific literature. Therewith, a highly advanced care domain,

especially in terms of clinical practice guideline quality, care networks, centralised quality assessment and certification, functioned as reference application domain for this doctoral thesis. Since the method does not include specifics for cancer care, it is applicable to other fields of integrated care for patients with complex, long-term health conditions. It should be tested and validated outside the realm of cancer care though, to confirm general applicability and to gain more insights into potential for improvement of the patient pathway method. The same applies to the application of the patient pathway questionnaire in other care domains to further validate the proposed definition.

Further, the DSR artefact of this work contributes to the IS knowledge base as argued in section 4.1 (principle of originality). The artefact's design is justified using scientific methods and reasoning. The defined requirements allow the validation of the patient pathway method (principle of justification). The potential benefits of the artefact designed were assessed with the preliminary study on the expected impact of the patient pathway approach (see section 3.3.3) and with the assessment after the method demonstration. The method shows to be beneficial for the relevant stakeholder groups (principle of benefit). Still, the focus of benefit assessment was rather on the template-based approach in general and on the development phase of the patient pathway method. A further evaluation of benefits also covering the subsequent method phases, i. e. implementation, usage and continuous improvement of patient pathways and templates, is necessary at a later time. With this regard, the dimensions and categories of the process quality framework for integrated care (see section 3.4.1) can function as foundation for the definition of further evaluation criteria.

The patient pathway method proposed features the necessary method elements and characteristics as described by Greiffenberg (2004), i. e. it has guidance character, a clear goal definition, and a definition of tasks and task bearers needed to achieve this goal (systematic characteristic). The method provides a procedural framework and details it for the development of patient pathways. It provides a role model and describes inputs and outputs. As discovered with the method assessment (paper P4, see section 3.3.2), a stronger integration of the evidence base throughout the Pa^{2}D-method's phases is desirable. With this regard, a deeper methodical integration of approaches for deriving pathway elements from evidence-based clinical practice guidelines (e. g. Schlieter et al. (2012)) or even with the development process of clinical practice guidelines should be considered. Furthermore, the presented approach of integrating quality indicators in pathway models could be embedded in a larger context of pathway-based quality management. Therefore, the possibilities to integrate the patient pathway method's phases of evaluation and continuous follow-up with common quality management systems applied in the healthcare sector, e. g. according to the ISO 9001 standard or the sector-specific DIN EN 15224 standard, should be analysed. This could enable a pathway-driven quality management and monitoring along the patient pathways of integrated care networks (Richter et al. (2016)).

In the realm of reference modelling, the work of this thesis shapes the organisational and methodical frame of the template-based approach as reference modelling approach and describes requirements for the reference model and application models (vom Brocke (2015)). The patient pathway method implements the typical procedure of reference modelling projects as for example described by Fettke and Loos (2007). To continue the work on the patient pathway method, two major open fields of action remain, stemming from the realm of reference modelling. One open issue concerns the construction process, especially the analysis of suitable and useful construction techniques for the development of network-specific, template-based patient pathways as application models. Also, the representation of such techniques in patient pathway templates to best support the construction of application models is of further interest. Currently, annotations and narrative descriptions are used for adaptable pathway parts. Thus, following studies should detail the implementation phase of the Pa^{2}D-method. The second major field of action is the technological support for the template-based patient pathway approach. A technical platform for model creation, storage, exchange, and discussion (referred to as the patient pathway template repository in paper P4, see section 3.3.2) is needed. Suitable modelling tools and collaboration systems for patient pathway template development and implementation projects need to be analysed and provided.

As patient pathways differ from other pathway approaches in particular due to their patient-centredness, further possibilities for patient involvement throughout all phases of the patient pathway framework should be explored. According to the Pa^{2}D-method, patients or patient representatives are involved as (template) stakeholders in the development and implementation phases. Also, a patient pathway dedicates a separate view specifying tasks to be performed by the patient. The initial intent of operationalising patient-centredness should be intensified. This concerns, for example, the analysis and inclusion of suitable tools or methods of patient empowerment and patient engagement throughout all phases of the patient pathway method as for example already picked up by Hickmann et al. (2021). Furthermore, providing digital patient tools incorporating and displaying the individual patient pathway enriched with necessary information regarding its steps and decision points could support with increasing the confidence in decision-making, pathway adherence, patient information and satisfaction or even health outcomes. The evidence of such influences of patient pathways needs further investigation.

In summary, this work unifies the understanding of patient pathways by providing key characteristics and by proposing a definition of the term. It provides methical support for the development and implementation of patient pathways and applies an innovative template-based approach with this regard. Moreover, it supports the utilisation of patient pathways for quality management of integrated care networks by providing a mechanism to represent a quality perspective in conceptual pathway models. This paves the way for more integrated and at the same time patient-centred health care services of uniformly high quality.

References

Albreht, T., Amati, C., Angelastro, A., Asioli, M., Amunni, G., Barceló, A. M., Berling, C., Caraceni, A., Colamesta, V., Comiskey, K., Conroy, F., Hynes, M., Cusack, M., O'Connor, L., D'Angelo, D., Dusek, L., Kaasa, S., Kowalski, C., Lin, Y., Federici, A., Loupakis, F., La Torre, G., Luzzatto, L., Majiek, O., Nicoletti, G., Pasqualetti, G., Pérez, R. P., Pigni, A., Puccetti, C., Rossi, E., Sant, M., Tognetti, J., Trama, A., and Wesselmann, S. (2017). Integrated cancer control: The case for comprehensive cancer care networks (CCCN). In Albreht, T., Kiasuwa, R., and Van der Bulcke, M., editors, *European Guide on Quality Improvement in Comprehensive Cancer Control*, pages 77–103. Ljubljana: National Institute of Public Health; Brussels: Scientific Institute of Public Health.

Alexander, J. A., Lee, S.-Y. D., and Bazzoli, G. J. (2003). Governance forms in health systems and health networks. *Health Care Management Review*, 28(3):228–242.

Anderson, S., Allen, P., Peckham, S., and Goodwin, N. (2008). Asking the right questions: Scoping studies in the commissioning of research on the organisation and delivery of health services. *Health Research Policy and Systems*, 6(7).

Arah, O. A., Westert, G. P., Hurst, J., and Klazinga, N. S. (2006). A conceptual framework for the OECD Health Care Quality Indicators Project. *International Journal for Quality in Health Care: Journal of the International Society for Quality in Health Care*, 18 Suppl 1:5–13.

Becker, J., Holten, R., Knackstedt, R., and Niehaves, B. (2003). Wissenschaftstheoretische Grundlagen und ihre Rolle für eine konsensorientierte Informationsmodellierung. In *Wissenschaftstheorie in Ökonomie und Wirtschaftsinformatik*, pages 307–334.

Becker, J., Holten, R., Knackstedt, R., and Niehaves, B. (2004). Epistemologische Positionierungen in der Wirtschaftsinformatik am Beispiel einer konsensorientierten Informationsmodellierung. In Frank, U., editor, *Wissenschaftstheorie in Ökonomie und Wirtschaftsinformatik: Theoriebildung und -bewertung, Ontologien, Wissensmanagement*, Wirtschaftswissenschaft, pages 335–336. Wiesbaden: Deutscher Universitätsverlag.

Beckmann, M. W., Schlieter, H., Richter, P., and Wesselmann, S. (2016). Considerations on the improved integration of medical guidelines into routine clinical practice – a review and concept proposal. *Geburtshilfe und Frauenheilkunde*, 76(4):369–376.

Bokhour, B. G., Fix, G. M., Mueller, N. M., Barker, A. M., Lavela, S. L., Hill, J. N., Solomon, J. L., and Lukas, C. V. (2018). How can healthcare organizations implement patient-centered

care? Examining a large-scale cultural transformation. *BMC Health Services Research*, 18(1):168.

Braun, R. and Esswein, W. (2006). Eine Methode zur Konzeption von Forschungsdesigns in der konzeptuellen Modellierungsforschung. In Schelp, J., Winter, R., Frank, U., Rieger, B., and Turowski, K., editors, *Integration, Informationslogistik und Architektur*, pages 143–171. Bonn: Gesellschaft für Informatik e.V.

Braun, R. and Schlieter, H. (2014). Requirements-based development of BPMN extensions: The case of clinical pathways. In *Proceedings of the 2014 IEEE 1st International Workshop on the Interrelations Between Requirements Engineering and Business Process Management (REBPM)*, pages 39–44.

Braun, R., Schlieter, H., Burwitz, M., and Esswein, W. (2014). BPMN4CP: Design and implementation of a BPMN extension for clinical pathways. In *Proceedings of the IEEE International Conference on Bioinformatics and Biomedicine (BIBM)*, pages 9–16.

Braun, R., Schlieter, H., Burwitz, M., and Esswein, W. (2016). BPMN4CP revised – extending BPMN for multiperspective modeling of clinical pathways. In *Proceedings of the 49th Hawaii International Conference on System Sciences*. IEEE.

Brook, R. H., McGlynn, E. A., and Shekelle, P. G. (2000). Defining and measuring quality of care: a perspective from US researchers. *International Journal for Quality in Health Care: Journal of the International Society for Quality in Health Care*, 12(4):281–295.

Bundesministerium für Gesundheit (2018). Gesundheitsziele. URL: https://www.bundesgesundheitsministerium.de/themen/gesundheitswesen/gesundheitsziele.html (last accessed: 01.03.2021).

Castro, E. M., Van Regenmortel, T., Vanhaecht, K., Sermeus, W., and Van Hecke, A. (2016). Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review. *Patient Education and Counseling*, 99(12):1923–1939.

De Bleser, L., Depreitere, R., De Waele, K., Vanhaecht, K., Vlayen, J., and Sermeus, W. (2006). Defining pathways. *Journal of Nursing Management*, 14(7):553–563.

De Luc, K. (2001). *Developing Care Pathways – The Handbook*. Radcliffe Medical Press Ltd., 1st edition.

Deutsche Forschungsgemeinschaft (2013). *Sicherung guter wissenschaftlicher Praxis*. John Wiley & Sons, Ltd. URL: https://onlinelibrary.wiley.com/doi/abs/10.1002/9783527679188.oth1 (last accessed: 01.03.2021).

Expert Group on Health Systems Performance Assessment (2017). *BLOCKS – Tools and Methodologies to Assess Integrated Care in Europe*. European Commission, Luxembourg: Publications Office of the European Union.

Fettke, P. and Loos, P. (2007). Perspectives on reference modeling. In Fettke, P. and Loos, P., editors, *Reference Modeling for Business Systems Analysis*, pages 1–20. Hershey, London: IGI Publishing.

Francke, A. L., Smit, M. C., de Veer, A. J., and Mistiaen, P. (2008). Factors influencing the implementation of clinical guidelines for health care professionals: A systematic meta-review. *BMC Medical Informatics and Decision Making*, 8(1):38.

Frank, U. (2007a). Ein Vorschlag zur Konfiguration von Forschungsmethoden in der Wirtschaftsinformatik. In Lehner, F. and Zelewski, S., editors, *Wissenschaftstheoretische Fundierung und wissenschaftliche Orientierung der Wirtschaftsinformatik*, pages 158–185. Berlin: GITO.

Frank, U. (2007b). Evaluation of reference models. In Fettke, P. and Loos, P., editors, *Reference Modeling for Business Systems Analysis*, pages 118–140. Hershey, London: IGI Publishing.

Fumagalli, L. P., Radaelli, G., Lettieri, E., Bertele', P., and Masella, C. (2015). Patient empowerment and its neighbours: clarifying the boundaries and their mutual relationships. *Health Policy (Amsterdam, Netherlands)*, 119(3):384–394.

Grant, M. J. and Booth, A. (2009). A typology of reviews: An analysis of 14 review types and associated methodologies. *Health Information and Libraries Journal*, 26(2):91–108.

Greenwood, J. E. (2006). Development of patient pathways for the surgical management of burn injury. *ANZ Journal of Surgery*, 76(9):805–811.

Greiffenberg, S. (2004). *Methodenentwicklung in Wirtschaft und Verwaltung*. Hamburg: Kovac.

Happel, H. J. and Seedorf, S. (2006). Applications of ontologies in software engineering. In *Proceedings of 2nd International Workshop on Semantic Web Enabled Software Engineering (SWESE 2006) held at the 5th International Semantic Web Conference (ISWC 2006)*.

Hevner, A. (2007). A three cycle view of design science research. *Scandinavian Journal of Information Systems*, 19(2). Article 4.

Hevner, A. and Chatterjee, S. (2010). Design science research in information systems. In *Design Research in Information Systems: Theory and Practice*, number 22 in Integrated Series in Information Systems, pages 9–22. Springer.

Hevner, A., March, S., Park, J., and Ram, S. (2004). Design science in information systems research. *Management Information Systems Quarterly*, 28(1):75–105.

Hickmann, E., Richter, P., and Schlieter, H. (2021). Let's get engaged: On the evidence of patient engagement tools and their integration in patient pathways. In *Proceedings of the 16th International Conference on Wirtschaftsinformatik (WI2021)*.

Hujala, A., Taskinen, H., and Rissanen, S. (2016). Policy Brief 26. How to support integration to promote care for people with multimorbidity in Europe?

Kayser, L., Karnoe, A., Duminski, E., Somekh, D., and Vera-Muñoz, C. (2019). A new understanding of health related empowerment in the context of an active and healthy ageing. *BMC Health Services Research*, 19(1):242.

Kinsman, L., Rotter, T., James, E., Snow, P., and Willis, J. (2010). What is a clinical pathway? Development of a definition to inform the debate. *BMC Medicine*, 8:31–33.

Kirchmer, M. (2009). Reference models to empower MPE. In *High Performance Through Process Excellence: From Strategy to Operations*, pages 85–100. Berlin, Heidelberg: Springer.

Kodner, D. L. and Kyriacou, C. K. (2000). Fully integrated care for frail elderly: two American models. *International Journal of Integrated Care*, 1:e08.

Kodner, D. L. and Spreeuwenberg, C. (2002). Integrated care: meaning, logic, applications, and implications – a discussion paper. *International Journal of Integrated Care*, 2(4).

Kopp, I., Encke, A., and Lorenz, W. (2002). Leitlinien als Instrument der Qualitätssicherung in der Medizin. Das Leitlinienprogramm der Arbeitsgemeinschaft Wissenschaftlicher Medizinischer Fachgesellschaften (AWMF). *Bundesgesundheitsblatt – Gesundheitsforschung – Gesundheitsschutz*, 45(3):223–233.

Kowalski, C., Graeven, U., von Kalle, C., Lang, H., Beckmann, M. W., Blohmer, J.-U., Burchardt, M., Ehrenfeld, M., Fichtner, J., Grabbe, S., Hoffmann, H., Iro, H., Post, S., Scharl, A., Schlegel, U., Seufferlein, T., Stummer, W., Ukena, D., Ferencz, J., and Wesselmann, S. (2017). Shifting cancer care towards multidisciplinarity: the cancer center certification program of the German cancer society. *BMC cancer*, 17(1):850.

Langer, T. and Follmann, M. (2015). Das Leitlinienprogramm Onkologie (OL): Nukleus einer evidenzbasierten, patientenorientieren, interdisziplinären Onkologie? *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen*, 109(6):437–444.

Livieri, B., Cagno, P. D., and Bochicchio, M. (2015). A bibliometric analysis and review on performance modeling literature. *Complex Systems Informatics and Modeling Quarterly*, 2:56–71.

March, S. T. and Smith, G. F. (1995). Design and natural science research on information technology. *Decision Support Systems*, 15(4):251–266.

Minkman, M. (2012). The current state of integrated care: an overview. *Journal of Integrated Care*, 20(6):346–358.

Minkman, M. (2016). The Development Model for Integrated Care: A validated tool for evaluation and development. *Journal of Integrated Care*, 24(1):38–52.

Minkman, M., Ahaus, K., Fabbricotti, I., Nabitz, U., and Huijsman, R. (2009). A quality management model for integrated care: results of a delphi and concept mapping study. *International Journal for Quality in Health Care: Journal of the International Society for Quality in Health Care*, 21(1):66–75.

Mould, G., Bowers, J., and Ghattas, M. (2010). The evolution of the pathway and its role in improving patient care. *BMJ Quality and Safety in Health Care*, 19(5):e14.

Niehaves, B. (2005). Epistemological perspectives on multi-method information systems research. In *Proceedings of the European Conference of Information Systems (ECIS 2005)*. Paper 120.

Offermann, P., Levina, O., Schönherr, M., and Bub, U. (2009). Outline of a design science research process. In *Proceedings of the 4th International Conference on Design Science Research in Information Systems and Technology (DESRIST 2009)*, pages 1–11. New York: Association for Computing Machinery.

Ollenschläger, G., Kirchner, H., and Fiene, M. (2001). Leitlinien in der Medizin – Scheitern sie an der praktischen Umsetzung? *Der Internist*, 42(4):473–483.

Österle, H., Becker, J., Frank, U., Hess, T., Karagiannis, D., Krcmar, H., Loos, P., Mertens, P., Oberweis, A., and Sinz, E. J. (2011). Memorandum on design-oriented information systems research. *European Journal of Information Systems*, 20(1):7–10.

Peffers, K., Tuunanen, T., and Niehaves, B. (2018). Design science research genres: Introduction to the special issue on exemplars and criteria for applicable design science research. *European Journal of Information Systems*, 27(2):129–139.

Peffers, K., Tuunanen, T., Rothenberger, M. A., and Chatterjee, S. (2007). A design science research methodology for information systems research. *Journal of Management Information Systems*, 24(3):45–77.

Peters, M. D. J., Godfrey, C. M., Khalil, H., Mcinerney, P., Parker, D., and Soares, C. B. (2015). Guidance for conducting systematic scoping reviews. *International Journal of Evidence-based Healthcare*, 13(3):141–146.

Richter, P. (2019). Bringing care quality to life: Towards quality indicator-driven pathway modelling for integrated care networks. In *Proceedings of the 27th European Conference on Information Systems (ECIS 2019)*.

Richter, P., Burwitz, M., and Esswein, W. (2016). Conceptual considerations on the integration of quality indicators into clinical pathways. *Studies in Health Technology and Informatics*, 228 – Exploring Complexity in Health: An Interdisciplinary Systems Approach:38–42.

Richter, P. and Schlieter, H. (2019a). 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*, (34):105.

Richter, P. and Schlieter, H. (2019b). Process-based quality management in care: Adding a quality perspective to pathway modelling. In Panetto, H., Debruyne, C., Hepp, M., Lewis, D., Ardagna, C. A., and Meersman, R., editors, *On the Move to Meaningful Internet Systems: OTM 2019 Conferences*, Lecture Notes in Computer Science, pages 385–403. Springer International Publishing.

Richter, P. and Schlieter, H. (2019c). Understanding patient pathways in the context of integrated health care services – Implications from a scoping review. In *Proceedings of the 14th International Conference on Wirtschaftsinformatik (WI 2019)*, pages 997–1011.

Richter, P. and Schlieter, H. (2020). Paving the way for patient pathways: Synthesizing a user-centered method design with results from a systematic literature review. In *Proceedings of the 15th International Conference on Wirtschaftsinformatik (WI 2020)*.

Richter, P. and Schlieter, H. (2021). Patient pathways for comprehensive care networks – A development method and lessons from its application in oncology care. In *Proceedings of the 54th Hawaii International Conference on System Sciences (HICSS 2021)*, pages 3753–3763.

Schlieter, H., Juhrisch, M., Dietz, G., and Esswein, W. (2012). Governance in hospitals – The case of business process alignment. In *Proceedings of the 18th America's Conference on Information Systems (AMCIS 2012)*. Article 30.

Smith, S. M. and O'Dowd, T. (2007). Chronic diseases: What happens when they come in multiples? *British Journal of General Practice*, 57(537):268–270.

Sung, H., Ferlay, J., Siegel, R. L., Laversanne, M., Soerjomataram, I., Jemal, A., and Bray, F. (2021). Global cancer statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: A Cancer Journal for Clinicians*.

Uschold, M. (1996). Building ontologies: Towards a unified methodology. In *Expert Systems '96*.

Valentijn, P. P., Schepman, S. M., Opheij, W., and Bruijnzeels, M. A. (2013). Understanding integrated care: A comprehensive conceptual framework based on the integrative functions of primary care. *International Journal of Integrated Care*, 13:e010.

Vanhaecht, K., Gerven, E. V., Deneckere, S., Lodewijckx, C., Janssen, I., Zelm, R. v., Boto, P. A. F., Mendes, R. V., Panella, M., Biringer, E., and Sermeus, W. (2012). The 7-phase method to design, implement and evaluate care pathways. *The International Journal of Person Centered Medicine*, 2(3):341–351.

vom Brocke, J. (2015). *Referenzmodellierung. Gestaltung und Verteilung von Konstruktionsprozessen*. Berlin: Logos Verlag, 2nd edition.

Wicke, C., Teichmann, R., Holler, T., Rehder, F., and Becker, H. D. (2004). Design and use of patient pathways in general surgery. *Chirurg*, 75(9):907–915.

World Health Organization (2016). *Framework on integrated, people-centred health services. Report by the Secretariat*. 69th World Health Assembly. Provisional agenda item 16.1, URL: http://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_39-en.pdf (last accessed: 16.01.2021).

Zonneveld, N., Driessen, N., Stüssgen, R., and Minkman, M. (2018). Values of integrated care: A systematic review. *International Journal of Integrated Care*, 18(4):9, 1–12.

Part II
Doctoral Thesis Papers

5 Paper P1

Table 3: Key information on paper P1 and declaration of authorship.

Paper P1	
Title	**Understanding Patient Pathways in the Context of Integrated Health Care Services – Implications from a Scoping Review**
Author(s)	Peggy Richter (PR) Hannes Schlieter (HS)
Publication	Ludwig, T. and Pipek, V. (eds.): *Human Practice. Digital Ecologies. Our Future.* Proceedings of the 14th International Conference on Wirtschaftsinformatik (WI 2019), 24.02. – 27.02.2019, Siegen, Germany, pp. 987-1001
Reference	Richter and Schlieter (2019c)
Available at	https://aisel.aisnet.org/wi2019/track08/papers/6/
Author's contribution[5]	Conception: PR 80%, HS 20% Data processing, evaluation and interpretation: PR 60%, HS 40% Formulation of the manuscript: PR 90%, HS 10%
Additional materials	-

---

[5]The contributions of the author(s) are structured according to the authorship criteria of the German Research Foundation for good scientific practice (Deutsche Forschungsgemeinschaft (2013)).

6 Paper P2

Table 4: Key information on paper P2 and declaration of authorship.

Paper P2	
Title	**Validating the Concept of Patient Pathways: A European Survey on Their Characteristics, Definition and State of Practice**
Author(s)	Peggy Richter (PR)
	Emily Hickmann (EH)
	Hannes Schlieter (HS)
Publication	Proceedings of the 25th Pacific Asia Conference on Information Systems (PACIS 2021), 20.06. – 24.06.2021, Dubai, Emirate of Dubai
Reference	-
Available at	https://aisel.aisnet.org/pacis2021/32
Author's contribution[6]	Conception:
	PR 70%, EH 25%, HS 5%
	Data processing, evaluation and interpretation:
	PR 70%, EH 5%, HS 25%
	Formulation of the manuscript:
	PR 50%, EH 40%, HS 10%
Additional materials	Appendix C - Questionnaire of the online patient pathway survey in the domain of oncology care

---

[6]The contributions of the author(s) are structured according to the authorship criteria of the German Research Foundation for good scientific practice (Deutsche Forschungsgemeinschaft (2013)).

7 Paper P3

Table 5: Key information on paper P3 and declaration of authorship.

Paper P3	
Title	**Paving the Way for Patient Pathways: Synthesizing a User-Centered Method Design with Results from a Systematic Literature Review**
Author(s)	Peggy Richter (PR)
	Hannes Schlieter (HS)
Publication	Proceedings of the 15th International Conference on Wirtschaftsinformatik (WI 2020), 08.03. – 11.03.2020, Potsdam, Germany
Reference	Richter and Schlieter (2020)
Available at	`https://doi.org/10.30844/wi_2020_f6-richter`
Author's contribution[7]	Conception:
	PR 80%, HS 20%
	Data processing, evaluation and interpretation:
	PR 80%, HS 20%
	Formulation of the manuscript:
	PR 90%, HS 10%
Additional materials	Appendix D - Complete list of user stories collected

---

[7]The contributions of the author(s) are structured according to the authorship criteria of the German Research Foundation for good scientific practice (Deutsche Forschungsgemeinschaft (2013)).

8 Paper P4

Table 6: Key information on paper P4 and declaration of authorship.

Paper P4	
Title	**Patient Pathways for Comprehensive Care Networks – A Development Method and Lessons from its Application in Oncology Care**
Author(s)	Peggy Richter (PR) Hannes Schlieter (HS)
Publication	Proceedings of the 54th Hawaii International Conference on System Sciences (HICSS 2021), 05.01. – 08.01.2021, Kauai, Hawaii, USA, pp. 3753-3763
Reference	Richter and Schlieter (2021)
Available at	http://hdl.handle.net/10125/71071
Author's contribution[8]	Conception: PR 80%, HS 20% Data processing, evaluation and interpretation: PR 90%, HS 10% Formulation of the manuscript: PR 90%, HS 10%
Additional materials	Appendix D - Complete list of user stories collected Appendix E - Questionnaire for the assessment of the Pa^{2}D-method

---

[8]The contributions of the author(s) are structured according to the authorship criteria of the German Research Foundation for good scientific practice (Deutsche Forschungsgemeinschaft (2013)).

9 Paper P5

Table 7: Key information on paper P5 and declaration of authorship.

Paper P5	
Title	**Bringing Care Quality to Life: Towards Quality Indicator-Driven Pathway Modelling for Integrated Care Networks**
Author(s)	Peggy Richter (PR)
Publication	Proceedings of the 27th European Conference on Information Systems (ECIS 2019), 11.06. – 14.06.2019, Stockholm & Uppsala, Sweden
Reference	Richter (2019)
Available at	https://aisel.aisnet.org/ecis2019_rip/14
Author's contribution[9]	Conception: PR 100% Data processing, evaluation and interpretation: PR 100% Formulation of the manuscript: PR 100%
Additional materials	-

---

[9]The contributions of the author(s) are structured according to the authorship criteria of the German Research Foundation for good scientific practice (Deutsche Forschungsgemeinschaft (2013)).

10 Paper P6

Table 8: Key information on paper P6 and declaration of authorship.

Paper P6	
Title	**Process-Based Quality Management in Care: Adding a Quality Perspective to Pathway Modelling**
Author(s)	Peggy Richter
	Hannes Schlieter
Publication	Panetto H., Debruyne C., Hepp M., Lewis D., Ardagna C., Meersman R. (eds.): *On the Move to Meaningful Internet Systems*: OTM 2019 Conferences, OTM 2019, Lecture Notes in Computer Science 11877, pp. 385-403
Reference	Richter and Schlieter (2019b)
Available at	https://doi.org/10.1007/978-3-030-33246-4_25
Author's contribution[10]	Conception:
	PR 80%, HS 20%
	Data processing, evaluation and interpretation:
	PR 75%, HS 25%
	Formulation of the manuscript:
	PR 70%, HS 30%
Additional materials	-

---

[10]The contributions of the author(s) are structured according to the authorship criteria of the German Research Foundation for good scientific practice (Deutsche Forschungsgemeinschaft (2013)).

Part III
Appendices

Appendix A   Complete List of Publications

In Table 9, a list of all publications by the author is provided. The publications are ranked both according to the VHB-JOURQUAL3[11] ranking and the WKWI[12] ranking. If relevant, the acceptance rate (AR) is annotated additionally.

Table 9: Complete list of author's publications.

Publication	Ranking
2021	
H. Schlieter, P. Timpel, L. Otto, **P. Richter**, B. Wollschlaeger, A. Knapp, L. Harst: Digitale Gesundheitsanwendungen – Forderungen für deren Entwicklung, Implementierung und begleitende Evaluation. *Monitor Versorgungsforschung*, 02/2021, pp. 58–62.	–
E. Hickmann, **P. Richter**, H. Schlieter: Let's Get Engaged: On the Evidence of Patient Engagement Tools and Their Integration in Patient Pathways. In: Proceedings of the 16th *International Conference on Wirtschaftsinformatik* (WI 2021), 2021.	JQ3: C WKWI: B (AR: 35%)
P. Richter, H. Schlieter: Patient Pathways for Comprehensive Care Networks – A Development Method and Lessons from its Application in Oncology Care. In: Proceedings of the 54th *Hawaii International Conference on System Sciences* (HICSS 2021), Kauai, Hawaii, USA, 2021, pp. 3753–3763.	JQ3: C WKWI: B
2020	
P. Richter, H. Schlieter: Paving the Way for Patient Pathways: Synthesizing a User-Centered Method Design with Results from a Systematic Literature Review. In: N. Gronau, M. Heine, H. Krasnova, K. Pousttchi (eds.), Proceedings of the 15th *International Conference on Wirtschaftsinformatik* (WI 2020), Potsdam, Germany, 2020.	JQ3: C WKWI: B (AR: 32,8%)
L. Otto, L. Harst, P. Timpel, B. Wollschlaeger, **P. Richter**, H. Schlieter: Defining and Delimitating Telemedicine and Related Terms – An Ontology-Based Classification. In: A. J. Maeder, S. Champion, C. Moores, R. Golley (eds.): *Information Technology Based Methods for Health Behaviours*, 2020, IOS Press: Amsterdam, Berlin, Washington, DC, pp. 113–122.	–

---

[11]JQ3: VHB-JOURQUAL3 (2015):
https://vhbonline.org/en/vhb4you/vhb-jourqual/vhb-jourqual-3/complete-list

[12]WKWI: "WI-Orientierungsliste der WKWI" (2008):
http://www.kaifischbach.net/wkwi/orientierungslisten.pdf

Table 9: Complete list of author's publications *(continued)*.

Publication	Ranking
2019	
P. Richter, H. Schlieter: Process-Based Quality Management in Care: Adding a Quality Perspective to Pathway Modelling. In: H. Panetto, C. Debruyne, M. Hepp, D. Lewis, C. Ardagna, R. Meersman (eds.), On the Move to Meaningful Internet Systems: OTM 2019 Conferences, OTM 2019, *Lecture Notes in Computer Science* (LNCS) 11877, Springer, pp. 385–403.	JQ3: C WKWI: A (AR: 29,8%)
P. Richter: Bringing Care Quality To Life: Towards Quality Indicator-Driven Pathway Modelling In Health Care Networks. In: Proceedings of the 27th *European Conference on Information Systems* (ECIS 2019), Stockholm & Uppsala, Sweden, 2019, pp. 1–13.	JQ3: B WKWI: A (AR: 29,7%)
M. Benedict, H. Schlieter, M. Burwitz, T. Scheplitz, M. Susky, **P. Richter**, T. Ziemssen: Patientenintegration durch Pfadsysteme. In: T. Ludwig, V. Pipek (eds.), Proceedings of the 14th *International Conference on Wirtschaftsinformatik* (WI 2019), Siegen, Germany: Universitätsverlag Siegen, 2019, pp. 927–941.	JQ3: C WKWI: B (AR: 34%)
P. Richter, H. Schlieter: Understanding Patient Pathways in the Context of Integrated Health Care Services – Implications from a Scoping Review. In: T. Ludwig, V. Pipek (eds.), Proceedings of the 14th *International Conference on Wirtschaftsinformatik* (WI 2019), Siegen, Germany: Universitätsverlag Siegen, 2019, pp. 987–1001.	JQ3: C WKWI: B (AR: 34%)
M. Benedict, H. Schlieter, M. Burwitz, T. Scheplitz, M. Susky, **P. Richter**: A Reference Architecture Approach for Pathway-Based Patient Integration. In: Proceedings of the 23rd IEEE *International Enterprise Distributed Object Computing Conference* (EDOC 2019), Paris, France, 2019, pp. 58–66.	JQ3: – WKWI: B
L. Harst, P. Timpel, L. Otto, **P. Richter**, B. Wollschlaeger, H. Lantzsch, K. Winkler, H. Schlieter: An empirically derived taxonomy of telemedicine – development of a standardized codebook. In: 18th *Deutscher Kongress Versorgungsforschung* (DKVF), German Medical Science GMS Publishing House, 2019.	–
L. Harst, P. Timpel, L. Otto, **P. Richter**, B. Wollschlaeger, K. Winkler, H. Schlieter: Identifying Barriers in Telemedicine-Supported Integrated Care Research: Scoping Reviews and Qualitatitve Content Analysis. In: *Journal of Public Health*: From Theory to Practice, 2019, pp. 1–12.	–
P. Richter, H. Schlieter: 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. In: *Forum* 1, 2019, p. 105.	–

Table 9: Complete list of author's publications *(continued)*.

Publication	Ranking
P. Richter, H. Schlieter: Patientenpfade in der Onkologie – Hilfe zur Sicherstellung von Patientenzentriertheit und Versorgungskontinuität. In: *ONKOLOGIE heute* 18, 2019, pp. 38–39.	–
2018	
L. Harst, P. Timpel, L. Otto, B. Wollschlaeger, **P. Richter**, H. Schlieter: Identifying Obstacles and Research Gaps of Telemedicine Projects: Approach for a State-of-the-Art Analysis. In: *Studies in Health Technology and Informatics* 247, 2018, pp. 121–125.	–
L. Otto, L. Harst, H. Schlieter, B. Wollschlaeger, **P. Richter**, P. Timpel: Towards a Unified Understanding of eHealth and Related Terms – Proposal of a Consolidated Terminological Basis. In: Proceedings of the 11th *International Joint Conference on Biomedical Engineering Systems and Technologies* (BIOSTEC 2018) Volume 5: HEALTHINF, 2018, pp. 533–539.	–
2017	
–	–
2016	
R. Braun, H. Wendler, M. Benedict, M. Burwitz, K. Gand, **P. Richter**, R. Rößler, H. Schlieter, J. Stark, W. Esswein: Integrated Enterprise Modeling Lectures for Master Classes. In: Modellierung 2016, Workshop Volume 255 of *Lecture Notes in Informatics* (LNI), 2016, pp. 53–62.	JQ3: C WKWI: B
P. Richter, K. Gand, W. Esswein: Lifetime Electronic Health Records as an Enabler for Integrated Care. In: T. X. Bui, R. H. Sprague Jr. (eds.): Proceedings of the 49th *Hawaii International Conference on System Sciences* (HICSS 2016), Kauai, Hawaii, USA, 2016, pp. 3199–3207.	JQ3: C WKWI: B
P. Richter, M. Frank, H. Schlieter: Entwicklung eines Leitlinienmanagementsystems – Anforderungen und konzeptuelle Vorarbeiten. In: V. Nissen, D. Stelzer, S. Straßburger, D. Fischer (eds.), Proceeding of the *Multikonferenz Wirtschaftsinformatik* (MKWI 2016), Ilmenau, Germany: Universitätsverlag Ilmenau, 2016, pp. 679–690.	JQ3: D WKWI: C
P. Richter, M. Burwitz, W. Esswein: Conceptual Considerations on the Integration of Quality Indicators into Clinical Pathways. In: *Studies in Health Technology and Informatics* 228, 2016, pp. 38–42.	–
M. W. Beckmann, H. Schlieter, **P. Richter**, S. Wesselmann: Considerations on the Improved Integration of Medical Guidelines into Routine Clinical Practice – a Review and Concept Proposal. In: *Geburtshilfe und Frauenheilkunde* 76(4), 2016, pp. 369–376.	–

Table 9: Complete list of author's publications *(continued)*.

Publication	Ranking
2015	
K. Gand, **P. Richter**, W. Esswein: Application of Lifetime Electronic Health Records: Are we ready yet? In: Proceedings of the 28th *Bled eConference* #eWellbeing, 2015, pp. 217–227.	JQ3: – WKWI: C
K. Gand, **P. Richter**, W. Esswein: Towards Lifetime Electronic Health Record Implementation. In: D. Hayn, G. Schreier, E. Ammenwerth, A. Hörbst (eds.): *Studies in Health Technology and Informatics* 212: eHealth2015 – Health Informatics Meets eHealth, 2015, pp. 225–232.	–
2014	
T. Hess, C. Legner, W. Esswein, W. Maaß, C. Matt, H. Österle, H. Schlieter, **P. Richter**, R. Zarnekow: Digital Life as a Topic of Business and Information Systems Engineering? In: *Business & Information Systems Engineering* (BISE) 6, 2014, pp. 247–253.	JQ3: B WKWI: A[13]
P. Richter, W. Esswein: Betriebliche Prozesse und Projekte im Spannungsfeld zwischen Standardisierung und Agilität. In: D. Kundisch, L. Suhl and L. Beckmann (eds.), Proceedings of the *Multikonferenz Wirtschaftsinformatik* (MKWI 2014), Paderborn, Germany: Universität Paderborn, 2014, pp. 1075–1087.	JQ3: D WKWI: C

---

[13]The journal is listed under its former name "Wirschaftsinformatik".

Appendix B   Complete List of Conference Presentations

Table 10: Complete list of author's conference presentations.

Presentation title, conference, venue	Date
Let's Get Engaged: On the Evidence of Patient Engagement Tools and Their Integration in Patient Pathways. *International Conference on Wirtschaftsinformatik* (WI 2021), Track "Creating Value Through Digital Innovation in Health Care", online	09.03. – 11.03.2021
Patient Pathways for Comprehensive Care Networks – A Development Method and Lessons from its Application in Oncology Care. *Hawaii International Conference on System Sciences* (HICSS 2021), Track "Optimization, Simulation and IT for Healthcare Processes and Services", online	05.01. – 08.01.2020
Paving the Way for Patient Pathways: Synthesizing a User-Centered Method Design with Results from a Systematic Literature Review. *International Conference on Wirtschaftsinformatik* (WI 2020), Track "Digital Health & Well-being", Potsdam, Germany	09.03. – 11.03.2020
Patient Pathways. *Deutscher Krebskonkress* (DKK 2020), iPAAC Local Stakeholder Forum, Berlin, Germany	20.02.2020
Process-Based Quality Management in Care: Adding a Quality Perspective to Pathway Modelling. *International Conference on Cooperative Information Systems* (CoopIS 2019), Track "Human Aspects and Social Interaction", Rhodes, Greece	23.10. – 25.10.2019
Bringing Care Quality To Life: Towards Quality Indicator-Driven Pathway Modelling In Health Care Networks. *European Conference on Information Systems* (ECIS 2019), Stockholm & Uppsala, Sweden	11.06. – 14.06.2019
Governance of Comprehensive Cancer Care. *Brennpunkt Onkologie*, Berlin, Germany	16.05.2019
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. *Interdisciplinary Congress Quality of Cancer Care* (QoCC 2019), Berlin, Germany	28.03. – 29.03.2019
Entwicklung eines Leitlinienmanagementsystems – Anforderungen und konzeptuelle Vorarbeiten. *Multikonferenz Wirtschaftsinformatik* (MKWI 2016), Track "eHealth as a Service – Innovationen für Prävention, Versorgung und Forschung", Ilmenau, Germany	09.03. – 11.03.2016
Lifetime Electronic Health Records as an Enabler for Integrated Care. *European Conference on Information Systems* (ECIS 2015), Pre-ECIS Workshop "Patient-Centered Health Information Technology: Preparing for a New Era", Münster, Germany	26.05.2015

Table 10: Complete list of author's publications *(continued)*.

Presentation title, conference, venue	Date
Betriebliche Prozesse und Projekte im Spannungsfeld zwischen Standardisierung und Agilität. *Multikonferenz Wirtschaftsinformatik* (MKWI 2014), Track "Enterprise Modeling and Enterprise IS", Paderborn, Germany	26.02. – 28.02.2014

Appendix C   Questionnaire of the Online Patient Pathway Survey in the Domain of Oncology Care

The online patient pathway survey was used for the validation of the characteristics of patient pathways identified from the literature, to assess agreement with a proposed definition and the experiences of practitioners with patient pathways, representation formats, patient pathway usage, and potentials (see paper P2, section 3.2.2). It was adapted to the specifics of comprehensive cancer care. The description of CCCNs presented in the preface of the questionnaire is taken from Albreht et al. (2017). The survey was conducted among the members of work package 10 (WP10) of the iPAAC project and named accordingly.

Patient pathway survey among iPAAC WP 10 members

Dear iPAAC WP10 member,

we invite you to participate in this patient pathway survey that aims at examining the understanding and implementation of oncological patient pathways on the network level as well as personal experiences with patient pathways among iPAAC WP10 members. The survey draws upon general characteristics of patient pathways identified in a systematic scoping review. Based on this, a patient pathway definition is proposed and shall be rated by the survey participants. So, if you are, in any way, involved with patient pathways (e.g. in research, development, management, usage, analysis of patient pathways), we invite you to participate in this survey.

Thank you in advance for participating and kind regards from Dresden,

Peggy and Hannes

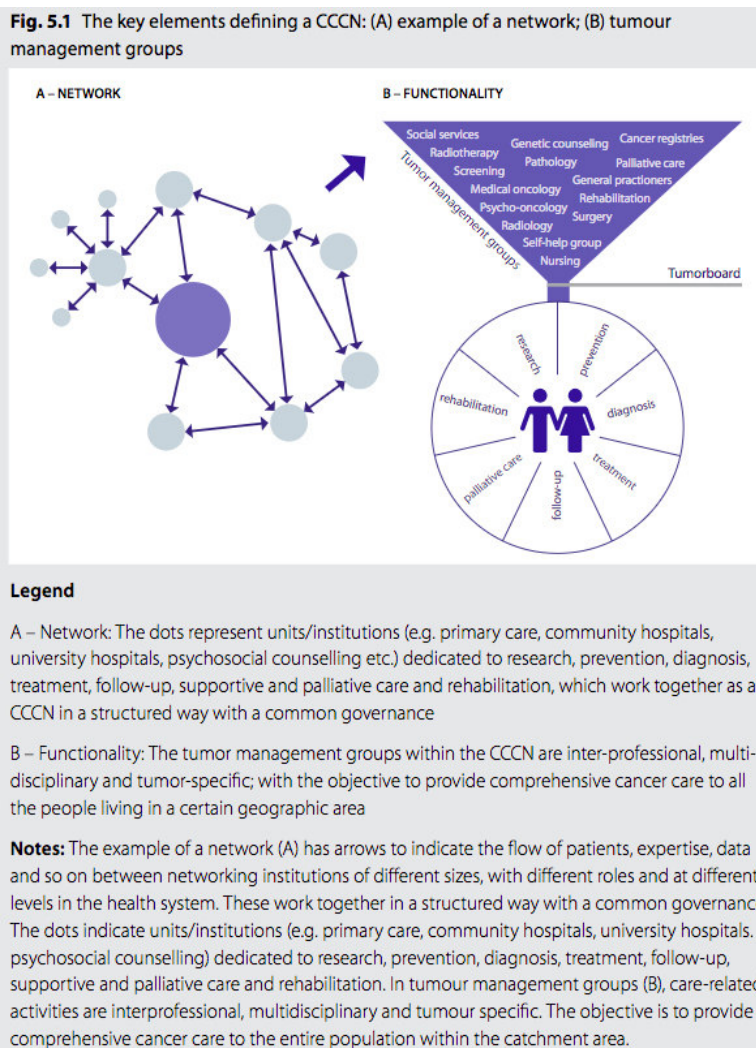There are 14 questions in this survey

CHARACTERISTICS OF PATIENT PATHWAYS

In the following, we address oncological patient pathways as intended to be implemented in networks for comprehensive cancer care in the iPAAC project. Such networks are named Comprehensive Cancer Care Networks (CCCNs) in the CANCON guide and are described as follows (please see pages 79 and 80 in the CANCON guide for reference and further information).

Box 5.1 Definition of a CCCN as used in this volume

• A CCCN consists of multiple units belonging to different institutions dedicated to research, prevention, diagnosis, treatment, follow-up, supportive and palliative care and rehabilitation for the benefit of cancer patients and cancer survivors. The key elements defining a CCCN are illustrated in Fig. 5.1.

• These units[a] interact and have a formal agreement to work together in a programmatic and structured way with common governance, in order to pursue their goals more effectively and efficiently through collective synergies.

• Within the CCCN the care of patients is the responsibility of interprofessional teams that are multidisciplinary and tumour specific. Each team or tumour management group works together for the benefit of patients with that particular type of tumour.

• Within the CCCN all units work together and adopt uniform standards of care for cancer-specific pathways that are binding for the entire network.

• The CCCN promotes a uniform system of quality assurance; and a unified informatics system for optimal exchange of information.

• The objective of a CCCN is to provide comprehensive cancer care to all the people living in a certain geographic area, thus pursuing equality and the improvement of outcomes and quality.

[a]The word unit is used to designate any component of a CCCN, whether an entire pre-existing institution or a part of an institution. For example, a unit might be an entire cancer centre, an oncology department of a general hospital or a children's hospital, a mammography facility, a pathology laboratory carrying out mutation analysis or a hospice.

Fig. 5.1 The key elements defining a CCCN: (A) example of a network; (B) tumour management groups

Legend

A – Network: The dots represent units/institutions (e.g. primary care, community hospitals, university hospitals, psychosocial counselling etc.) dedicated to research, prevention, diagnosis, treatment, follow-up, supportive and palliative care and rehabilitation, which work together as a CCCN in a structured way with a common governance

B – Functionality: The tumor management groups within the CCCN are inter-professional, multi-disciplinary and tumor-specific; with the objective to provide comprehensive cancer care to all the people living in a certain geographic area

Notes: The example of a network (A) has arrows to indicate the flow of patients, expertise, data and so on between networking institutions of different sizes, with different roles and at different levels in the health system. These work together in a structured way with a common governance. The dots indicate units/institutions (e.g. primary care, community hospitals, university hospitals. psychosocial counselling) dedicated to research, prevention, diagnosis, treatment, follow-up, supportive and palliative care and rehabilitation. In tumour management groups (B), care-related activities are interprofessional, multidisciplinary and tumour specific. The objective is to provide comprehensive cancer care to the entire population within the catchment area.

Please keep this approach in mind when answering the following questions regarding oncological patient pathways and to what extend they should cover the following characteristics. The characteristics were derived based on a scoping review on patient pathways literature.

[]

Purpose of use *

Please choose the appropriate response for each item:

	strongly agree	agree	neither agree nor disagree	disagree	strongly disagree
A patient pathway should describe and organise the key phases of care provision (e.g. diagnosis, treatment, follow-up, supportive and palliative/end-of-life care, rehabilitation/recovery).	○	○	○	○	○
A patient pathway should be used to inform and engage the patient.	○	○	○	○	○
A patient pathway should be use for documentation purposes (e.g. process and results documentation).	○	○	○	○	○
A patient pathways should be used for monitoring purposes (e.g. pathway compliance monitoring).	○	○	○	○	○
A patient pathway should be used for evaluation purposes (e.g. analysis of patient pathway usage or effects of patient pathway implementation).	○	○	○	○	○
A patient pathway should consider organisational goals of care (i.e. health care process and structure related goals).	○	○	○	○	○
A patient pathway should consider disease-related (medical) goals of care (i.e. aiming at the physical and mental well-being of patients).	○	○	○	○	○

	strongly agree	agree	neither agree nor disagree	disagree	strongly disagree
A patient pathway should consider individual treatment preferences of patients.	○	○	○	○	○
A patient pathway should be phase-oriented (i.e. patients all go through the same phases, but the moment and duration of the phases can vary).	○	○	○	○	○

[]

Focus *

Please choose the appropriate response for each item:

	strongly agree	agree	neither agree nor disagree	disagree	strongly disagree
A patient pathway should take planning and management of patient groups (patient types) into account.	○	○	○	○	○
A patient pathway should allow for individual patient planning and -management.	○	○	○	○	○

[]

Development *

Please choose the appropriate response for each item:

	strongly agree	agree	neither agree nor disagree	disagree	strongly disagree
A patient pathway should be developed and agreed to by a multidisciplinary team.	○	○	○	○	○
The development of a patient pathway should integrate the patient perspective (e.g. with focus group discussions).	○	○	○	○	○
During pathway development, medical evidence (e.g. clinical practice guidelines, standards) should be taken into account.	○	○	○	○	○
During pathway development, experts' experiences should be taken into account.	○	○	○	○	○
A patient pathway should take local conditions into account.	○	○	○	○	○
A patient pathway should take regional conditions into account.	○	○	○	○	○
A patient pathway should take national conditions into account.	○	○	○	○	○

[]

User Groups *

Please choose the appropriate response for each item:

	strongly agree	agree	neither agree nor disagree	disagree	strongly disagree
A patient pathway should be used by all involved professional care providers/units of the care network.	○	○	○	○	○
A patient pathway should be used by social services.	○	○	○	○	○
A patient pathway should be used by the patient.	○	○	○	○	○
A patient pathway should be used by patient's relatives (e.g. as informal caregivers).	○	○	○	○	○

[]

Are there other characteristics of patient pathways that are <u>not</u> covered with the proposed ones above?

Please write your answer here:

LimeSurvey - Online-Umfrage-Tool für sächsische Hochschulen ...   https://bildungsportal.sachsen.de/survey/limesurvey/index.php/a...

DEFINITION OF PATIENT PATHWAYS

Based on our literature study, we propose the following definition for patient pathways:

> *A patient pathway is a tool that permits the planning and management of the care process of individual patients within a group of similar patients with complex, long-term conditions. It defines the phases of care and supports mutual decision-making by the patient and a multidisciplinary care team collaborating in a comprehensive care network.*

[]Does this general definition cover the intended understanding of patient pathways in context of their implementation in Comprehensive Cancer Care Networks? Please leave a comment if you have suggestions for modification. *

Please choose **only one** of the following:

○ Yes

○ No

Make a comment on your choice here:

PATIENT PATHWAY PRACTICE

In this section, your practical experiences with patient pathways, existing initiatives and potentials of patient pathways are
addressed.

**[]Please provide further details on how you are involved with patient
pathways. ***

Please write your answer here:

**[]Considering your practical experience, are there other established terms
used synonymously for the patient pathway concept as described and
defined before?**

Please choose **all** that apply:

☐ No, the term patient pathway is understood and used as intended by the definition proposed before.

☐ Care pathway

☐ Integrated care pathway

☐ Clinical pathway

☐ Care map

☐ Treatment pathway

☐ Patient journey

☐ Other:

[]How is the term patient pathway understood in your country/ working environment so far?

Please choose **only one** of the following:

○ The term is understood and used as intended with the proposed definition.

○ The term is not in practical use.

○ The term is in practical use but understood differently (see comment).

Make a comment on your choice here:

[]

What kind of presentation/format of patient pathways have you experienced previously?

Please choose **all** that apply:

☐ Process models (e.g. flow charts, UML activity diagrams, BPMN models)

☐ MS Excel based

☐ Checklists

☐ Prosaic description

☐ Other:

**[]Patient pathways are said to have difficulty finding their way into practice.
Where do you see the greatest potentials of comprehensive cancer care
networks (CCCNs) to support the practical application of patient pathways
(i.e. what can CCCNs offer)? ***

Please choose **all** that apply:

☐ Methodological support for patient pathway development and implementation

☐ Technological support for patient pathway development and implementation

☐ Good example input from CCCN units for patient pathway development

☐ Centralized management of patient pathways (e.g. by specifying a responsible unit for patient

pathways)

☐ Involving the patient (e.g. in patient pathway development and implementation)

☐ Provision of seamless quality care across all involved units of the CCCN

☐ Continuous improvement (periodic reviews and updates) of patient pathways based on CCCN's

quality management efforts

☐ Other: _____

**[]Where do you see the greatest potentials of patient pathway usage for
Comprehensive Cancer Care Networks (CCCNs)? ***

Please choose **all** that apply:

☐ Increasing standardisation of care

☐ Improving compliance with clinical practice guidelines recommendations

☐ Improving quality of care

☐ Improving care coordination

☐ Other: _____

[]

Please use the following text field if you would like to provide us with further information, e.g. regarding patient pathway initiatives on national, regional, local or network-level you know and their status (e.g. planned, in development, implemented). You can provide us with links to websites and also send us further information/documents via e-Mail.

Please write your answer here:

ADDITIONAL INFORMATION

We would like to have the chance to get back to you, for example regarding existing patient pathway initiatives you informed us about. Also, we would appreciate it if you could provide us with more detailed information about yourself. This allows us to better understand your background and experience with patient pathways.

[]

If you like, you can provide us with additional information on yourself here.

Please write your answer(s) here:

Name	
E-Mail	
Position	
Scope of activities/responsibilities	
Department	
Organisation	
Country	

Submit your survey.
Thank you for completing this survey.

Appendix D   Complete List of User Stories

In Table 11, the full list of user stories (US) collected in February 2019 is presented. The user stories were used for the identification requirements and roles for the patient pathway method developed (see papers P3 and P4, sections 3.3.1 and 3.3.2). Typical abbreviations used are **CCCN** for comprehensive cancer care network, **PPD** for patient pathway development, and **PPW(s)** for patient pathway(s). Other abbreviations are clarified directly in the respective user stories in square brackets.

Table 11: Complete list of user stories.

No.	User story
US1	As a physician in a patient pathway development board I want to trace the diagnostic and therapeutic pathway of a patient using the technologies available so that there will be a comprehensive picture of the pathway.
US2	As a physician I want a standardized pathway structure so that within the CCCN, all the nodes of the network will be aligned in the provided services.
US3	As a health sciences researcher and coordinator involved in the patient pathway development I want the agreed definition of patient pathways to be piloted in several CCCNs so that it could become a commonly used tool for daily practice and benchmarking.
US4	As a patient I want to have a clear information/ plan what is the next step on the patient (my) pathway within CCCN with this type of cancer so that I feel "safe" not lost in a system.
US5	As a CCCN advisor I want an inspiring, workable, generic method for designing and implementing PPWs so that the CCCNs in the NL [Netherlands] achieve on applying PPWs for their regional patients suffering from 20 most common tumour types.
US6	As a OECI A&D [Organisation of European Cancer Institutes accreditation and designation] program coordinator I want a generic method and q[uality] indicators for PPWs on CCCNs to complement the OECI A&D standards.
US7	As a physician in a patient pathway development group I want to contribute to the development of (a) useful pathway(s) so that all colleagues in CCCNs can use these pathways across all networks and that all patients could benefit from them.
US8	As responsible of the Health Care Group at the EC-JRC [European Commission Joint Research Centre], I want to develop with the group/experts a patient care pathway for colorectal cancer. This will form the basis for the development of guidelines/ quality criteria for the individual components which will be defined as a priority for our activities.
US9	As a (healthcare) researcher I want conceptually clear and "easy to analyse" patient pathway representation so that it facilitates efficient, transparent and reproducible research.
US10	As a policy advisor I want "easy to manage" and inclusive of stakeholder opinion as well as of scientific evidence process of PP preparation so that it leads to high acceptance output.

Table 11: Complete list of user stories. *(continued)*

No.	User story
US11	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.
US12	As a quality manager I want to have a generic pathway as an example so that I/we have a frame for development of tumour specific pathways. This generic pathway should show all involved parties within the diagnostic/treatment path.
US13	As a medical doctor in training I want patient pathways to be based upon evidence-based guidelines so that I can provide quality of care.
US14	As a medical doctor in training I want patient pathways to be tumour-specific so that I can provide quality of care.
US15	As a medical doctor in training I want patient pathways to be adoptable to patient-specific situations (e.g. comorbidities, patient preferences) so that I can provide quality of care.
US16	As a practitioner, a physician in a patient pathway development and integration into real life I want the patient pathway will be easy to integrate so that all colleagues can discuss all problems and benefits across networks and between each other easy, not complicated.
US17	As a chair of a European Cancer Centre Accreditation Board I want to see a well-researched and published ideal template of a patient pathway so that CCCNs and Cancer Centres across Europe can achieve greater standardisation for patient benefit.
US18	As a new oncologist nurse at a centre (taking up a new job) I want to be able to see tumour-specific pathways for my centre/network so that I can provide timely and seamless diagnosis, treatment, and aftercare for my patients.
US19	As a methodologist in a PPD board I want to have definition of the group composition and management of CoI [cancer of interest] so that bias in PPD is controlled.
US20	As a methodologist in a PPD board I want to have information/agreement on consensus finding process so that bias in PPD is controlled.
US21	As a methodologist in a PPD board I want to have a described prioritisation process of topics integrated in the PPD in order to get transparency about the decision process.
US22	As a methodologist in a PPD board I want to have a description of the evidence base and the strength of certainty in order to get transparent and reproducible results.
US23	As a patient I want to integrate patient views and perspectives to be integrated in the process in order to integrate shared (informed) decision making in PPD.
US24	As a nurse I want to work in the development of patient pathways so that nursing specific care is ensured to patients from the moment of diagnosis until end-of-life or follow-up.

Table 11: Complete list of user stories. *(continued)*

No.	User story
US25	As a nurse I want to have specific patient pathways (tumour-related) with requirements for each phase of the care process so that care can be uniform, regulated and monitored/evaluated within different centres.
US26	As a representative of a multidisciplinary-multistakeholder organisation I would like the patient to get an access to optimal multidisciplinary cancer care at each stage of his/her pathway.
US27	As a manager I want the methodology to provide guidelines on the pathway development and identify the essential building blocks of a pathway so that pathways can be developed and adopted to the local healthcare context of the CCCN.
US28	As a physician in a patient pathway development I want a high consideration of PROMs [patient reported outcome measures] in the pathway so that patient reported outcomes are deeply considered in the pathway.
US29	As a patient I want a patient pathway that I can understand and that helps me make decisions together with my doctor and my family so that I can be in control of what is happening and to check if everything is going according to my expectations (for example those based on guidelines).
US30	As a technical expert in the boards I want to have a clear procedural advice for building the pathway.
US31	As a researcher I want to have a mean to include evidence-based information to the pathway.
US32	As national authority I want to have mechanisms to define obligatory tasks within the pathway.
US33	As a member of a CCCN I want to have agreed upon individualised 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.

Appendix E Questionnaire for the Assessment of the Pa²D-method

The online questionnaire was used to assess the fulfilment of the requirements for the Pa²D-method and the experiences with the application of the method for the development of a colorectal cancer patient pathway template (see Paper P4, section 3.3.2). The questionnaire was answered by the members of work package 10 (WP10) of the iPAAC project who were involved with the template development using the Pa²D-method.

Patient Pathway Template Development Method

With this survey, we would like to evaluate the method used for the development of the patient pathway template of CCCN care for colorectal cancer patients.

Dear iPAAC WP10 colleagues,

we would like to collect some feedback on how you experienced the development of the patient pathway template for CCCN care for colorectal cancer patients. This will help to improve the procedure for the development of the pancreatic cancer patient pathway template and in general.

Thank you in advance and best wishes

Peggy and Hannes

There are 4 questions in this survey.

Please indicate how much you agree with the statements (1: strongly agree ... 5: strongly disagree).

Please choose the appropriate response for each item:

	1	2	3	4	5
The patient pathways for comprehensive care networks have uniform template character and provide adaptation notes for their implementation to particular care networks.	○	○	○	○	○
The patient pathway templates are disease-specific, i.e. designed for a specific patient type.	○	○	○	○	○
The patient pathway templates are developed by a multi-stakeholder working group.	○	○	○	○	○
The patient pathway development method defined the group processes (group composition, roles, consensus finding, decision and prioritization processes, review processes).	○	○	○	○	○
The patient pathway templates are developed based on scientific evidence.	○	○	○	○	○

	1	2	3	4	5
The patient pathway templates sequence obligatory and optional steps and the relevant information along all phases of care in a comprehensive care network for the involved care providers and the patient.	○	○	○	○	○
The patient pathway templates provide a patient view to support shared decision-making and individualization to patient-specifics.	○	○	○	○	○

Please indicate your opinion: **The usage of a template-based patient pathway approach will... (1: strongly agree ... 5: strongly disagree)**

Please choose the appropriate response for each item:

	1	2	3	4	5
improve the quality of care	◯	◯	◯	◯	◯
create a uniformly high level of quality care	◯	◯	◯	◯	◯
reduce the risks and difficulties of patient pathway development for comprehensive care networks	◯	◯	◯	◯	◯
decrease costs of patient pathway development	◯	◯	◯	◯	◯
shorten the development time of patient pathways for comprehensive care networks	◯	◯	◯	◯	◯
increase the qualiy of patient pathways implemented in comprehensive care networks	◯	◯	◯	◯	◯
improve evidence-based practice	◯	◯	◯	◯	◯
increase reusability of patient pathways	◯	◯	◯	◯	◯
improve benchmarking of comprehensive care networks for the same patient populations	◯	◯	◯	◯	◯

How could the patient pathway template development process be improved?

Please write your answer here:

What did you like about the development process of the patient pathway template for colorectal cancer?

Please write your answer here:

Thank you very much for your feedback! We highly appreciate it.

Submit your survey.
Thank you for completing this survey.