Aalto-yliopisto
Aalto-universitetet
Aalto University

Master's Programme in Information Networks

Modelling Complex Patient Processes in a Multi-Producer Environment

A Design Science Approach Using Patient-Centred Modelling for Kidney Cancer Care Process

---

Essi Miettinen

Master's thesis
2025

Aalto-yliopisto
Aalto-universitetet
Aalto University

Author Essi Miettinen

Title of thesis Modelling Complex Patient Processes in a Multi-Producer Environment

Programme Information Networks

Major Strategy and Organizational Design

Thesis supervisor Professor Lauri Saarinen

Thesis advisor(s) D.Sc. (Tech.) Märt Vesinurm

Date 11.07.2025 **Number of pages** 104+18 **Language** English

Abstract

Complex healthcare services increasingly require more resources to fulfil the growing needs. Improving cost effectiveness while maintaining high quality of care is a universal goal. Designing and managing well-functioning patient care processes, as well as acknowledging and preventing shortcomings are noted as tools for delivering better care. Although multiple process modelling techniques have been proposed for this purpose, a universally common method is yet to be established.

This thesis explored process modelling approaches for complex patient processes and contributes to the ongoing search for a common modelling method. The challenge lies in the inherently fragmented nature of healthcare, where patient care spans multiple producers and decision-making is supported by clinical data and shared information between stakeholders. In addition, the growing emphasis on patient-centred care and the co-creation of health highlights the need for models that also support patient engagement and shared decision-making.

In this thesis, the term *patient journey* is primarily used to describe the patient's trajectory through the healthcare system across different producers, as it emphasises the actual care experience and patient perspective. The second core term *patient pathway* typically refers to a predefined planned care process.

This study applied a Design Science Research (DSR) approach. Understanding of the kidney cancer patient process was deepened through workshops with healthcare professionals, and the research problem and objectives were defined based on these discussions and relevant literature. Three modelling languages, Unified Modelling Language (UML), Business Process Model and Notation (BPMN) and Customer Journey Modelling Language (CJML), were compared in terms of their suitability for visualising the complex healthcare process of kidney cancer care. CJML was selected for the purpose due to its strengths in patient-centrality and its alignment with healthcare-specific requirements.

Through iterative modelling and expert validation, the CJML models for kidney cancer care were found to be comprehensive, though certain limitations were identified. CJML requires improved modelling capabilities to better represent decision-making, modular structures, sub-processes and repeating phases. Proposed developments, their reasoning and illustrative visualisations, were summarised in a compiled table and validated through expert feedback.

The findings contribute both a refined modelling artefact and practical guidance for modelling complex patient journeys. The thesis underlines the need for flexible modelling methods to address the specific characteristics of healthcare and contributes to the development of modelling approaches toward a unified practice.

Keywords Process modelling, patient journey, kidney cancer care, complex patient process, Customer Journey Modelling Language (CJML), Design Science Research, patient-centred care, co-creation of health

Aalto-yliopisto
Aalto-universitetet
Aalto University

Tekijä Essi Miettinen	
Työn nimi Monimutkaisten Potilashoitopolkujen Mallinnus Monituottajaympäristössä	
Koulutusohjelma Informaatioverkostot	
Pääaine Liiketoiminta ja Organisaatiomuotoilu	
Vastuuopettaja/valvoja Professori Lauri Saarinen	
Työn ohjaaja(t) Tekniikan tohtori Märt Vesinurm	
Päivämäärä 11.07.2025 **Sivumäärä** 104+18	**Kieli** englanti

Tiivistelmä

Monimutkaiset terveydenhuollon palvelut vaativat yhä enemmän resursseja vastatakseen kasvaviin tarpeisiin. On universaalisti tavoiteltua parantaa kustannustehokkuutta kuitenkaan hoidon laatua heikentämättä. Toimivien hoitoprosessien suunnittelu ja hallinta, sekä puutteiden tunnistaminen ja ehkäisy on nostettu keskeisiksi keinoiksi paremman hoidon tuottamiseen. Vaikka useita prosessimallinnusmenetelmiä on ehdotettu tähän tarkoitukseen, yhteistä ja yleisesti hyväksyttyä mallinnustapaa ei ole vielä löytynyt.

Tämä diplomityö tarkasteli mallinnusmenetelmiä monimutkaisille potilasprosesseille ja osallistuu yhteisen mallinnustavan löytämiseen. Työn haasteena oli terveydenhuollon hajanaisuus, jossa potilaspolut koostuvat useista palveluntuottajista ja päätöksenteko perustuu niin kliiniseen tietoon kuin tiedon jakamiseen eri sidosryhmien välillä. Lisäksi potilaslähtöisen hoidon ja sen yhdessä luominen edellyttävät korostuneesti mallinnustapoja, jotka tukevat potilaan aktiivista osallistumista niin päätöksentekoon kuin oman terveytensä edistämiseen.

Tässä työssä käytettiin ensisijaisesti käsitettä *potilasmatka* viittaamaan potilaan etenemiseen terveydenhuoltojärjestelmässä eri palveluntuottajien välillä, sillä se korostaa toteutunutta hoitoa ja potilaan näkökulmaa. Sen rinnalla esiintyy myös käsite *potilaspolku*, joka viittaa tyypillisesti ennalta määriteltyyn ja suunniteltuun hoitoprosessiin.

Tutkimuksessa käytettiin Design Science Research (DSR) -lähestymistapaa. Ymmärrystä munuaissyövän potilasprosessista syvennettiin työpajoissa terveydenhuollon asiantuntijoiden kanssa, ja näiden keskusteluiden sekä kirjallisuuden pohjalta määritettiin tutkimuksen ongelmat ja tavoitteet. Kolmea mallinnuskieltä, Unified Modelling Language (UML), Business Process Model and Notation (BPMN) ja Customer Journey Modelling Language (CJML), verrattiin niiden soveltuvuuden pohjalta monimutkaisen munuaissyöpähoidon potilasmatkan mallintamiseen. CJML valittiin jatkokehityksen kohteeksi, sillä sen potilaslähtöinen lähestyminen nähtiin kyvykkäänä vastaamaan terveydenhuollon erityisvaatimuksiin.

Iteratiivisen mallinnuksen ja asiantuntija-arvioinnin avulla CJML:n munuaissyöpämallinnukset todettiin kattaviksi, mutta puutteitakin tunnistettiin. CJML kaipaa lisämallinnuskeinoja päätöksenteon, moduulirakenteiden, osaprosessien ja toistuvien vaiheiden esittämiseen. Kehitysehdotukset, perustelut ja havainnollistavat visualisoinnit koottiin taulukkomuotoon ja arvioitiin asiantuntijapalautteen pohjalta.

Tutkimus kehittää mallinnusartefaktin sekä antaa käytännön suosituksia monimutkaisten potilasprosessien mallintamiseen. Diplomityö korostaa joustavien mallinnusmenetelmien tarvetta terveydenhuollon erityispiirteisiin soveltumiseen ja edistää samalla mallinnusmenetelmien kehittämistä kohti yhtenäistä käytäntöä.

Avainsanat Prosessimallinnus, potilasmatka, munuaissyövän hoito, monimutkainen potilasprosessi, Customer Journey Modelling Language (CJML), Design Science Research, potilaslähtöinen hoito, terveyden yhteisluominen

Aalto-yliopisto
Aalto-universitetet
Aalto University

Table of contents

Preface and acknowledgements

First of all, I am so incredibly ready to enjoy life again, see my friends and do absolutely nothing in my spare time. I did enjoy my thesis *journey,* at first, but the sun is shining, summer is here, and I cannot believe I’m closing this laptop for the last time.

Then to the official part. I want to thank my thesis advisor Märt Vesinurm for somehow luring me into this *process*. I definitely did not know what I was getting myself into, but I ended up enjoying the topic a lot. Also, thank you to Professor Paul Lillrank for offering me this opportunity and figuring out the funding. Thank you to Lauri Saarinen for supervising, and apologies for dropping the whole thing at you all at once without any prior warning.

Olipahan *prosessi*, kirjaimellisesti. En suosittele työskentelemään samanaikaisesti, mutta se nyt oli koko ajan tiedossa ja välillä taloustilanne vaatii venymisiä tällaisiin ratkaisuihin. Mutta eniten kannustan aloittamaan työn vasta, kun ymmärtää mistä siinä on kyse. Sillä voi välttyä paljolta lisätyöltä ja turhautumiselta.

I also want to thank my Markus for his endless support and kind words. I would not be here without you making me food and bringing me cups of coffee and tea.

And thank you to everyone else as well who has cheered me up when I’ve slept far too little or shown me empathy during the many days and nights I spent working on this.

After a very long spring, this thesis is now finally done, and I will be a diplomi-insinööri!!! <3

Somewhere close to Otaniemi, but already quite far, 11.07.2025

Essi Miettinen

List of Abbreviations

AD – Activity Diagram

BPMN – Business Process Modelling and Notation

ccRCC – Clear Cell Renal Cell Carcinoma

CG – Clinical Guidelines

CJML – Customer Journey Modelling Language

EHR – Electronic Health Records

EOL – End-of-Life

GP – General Practitioner

HCP – Healthcare Professional

HUS – Helsinki University Hospital

KCS – Kidney Cancer Specialist

OMG – Object Management Group

PC – Palliative Care

PJM – Patient Journey Mapping

PJD – Patient Journey Disruption

SD – Sequence Diagram

UML – Unified Modelling Language

1 Introduction

1.1 Background and motivation

As life expectancies increase and the human population grows, healthcare systems face increasing pressure to deliver complex, high-quality care at scale and adapt to the change (Barbagallo et al., 2015). Increasing demand for resources is evident especially with chronic diseases and multi-morbidity condition patients (Valentijn et al., 2013). Patients with complex diagnostics account for a large part of healthcare system resources, while the quality of care does not consistently meet expectations and intensions (Haywood et al., 2006). This creates urgent production-economic challenges: healthcare producers must optimise processes to ensure efficiency without compromising patient outcomes.

Addressing the widespread impact of chronic diseases has become a central priority for healthcare organisations, policymakers and governments (Danaher et al., 2024). One way healthcare producers can support these goals is by encouraging patients to take a more active role in managing their own illness (Ahn et al., 2015). However, meaningful patient involvement requires transparent and well-coordinated care pathways, which remain difficult to achieve in healthcare systems characterised by fragmented responsibilities and multiple detached producers (Vesinurm, 2025). This fragmentation often leads to a lack of shared understanding of patient care processes and their planning (Seys et al., 2019). Consequently, the modelling and clear representation of care pathways become critical enablers for improving both patient engagement and operational efficiency.

However, achieving such clarity is far from simple. The underlying challenge is the complexity of care systems themselves which pose challenges for daily patient care (Halvorsrud et al., 2018). Patient pathways themselves are inherently complex concepts operating within equally complex healthcare systems (Seys et al., 2019). This dual complexity forms the central challenge that this thesis seeks to address.

Simultaneously improving cost effectiveness of healthcare services and operations, without compromising care quality is a widely shared goal across health systems. Optimising healthcare processes necessitates acknowledging the interconnected nature of each stage within the patient care continuum (Healthcare Financial Management, 2003; Zapka et al., 2003). Integration of care processes and information flow is essential, not only within individual care episodes but across the entire healthcare enterprise.

In this context, process modelling plays a foundational role by clarifying how care is structured, delivered and supported through information. This understanding is also essential for making effective use of health data systems like electronic health records (EHR). For instance, EHRs can help identify patients at risk of diagnostic delays due to missed follow-ups (Murphy et al., 2014), or improve clinical practice and continuity of care (Reis et al., 2017). Enhanced use of EHR data is also expected to contribute to the rebalancing of healthcare economics. However, having EHR does not ensure that data can be meaningfully reused, information must also be accessible and structured in a way that supports practical use (Vesinurm, Sylgren, et al., 2024).

Therefore, process models do not only guide care planning but also enable the purposeful application of data within systems like EHR. The complexity of patient pathways has led to a growing interest in using modelling languages to represent them. Process modelling offers methods to, for example, evaluate costs, resource consumption and spot bottlenecks (Combi et al., 2017). However, applying modelling languages in healthcare requires careful consideration of the unique challenges and complexities inherent in care processes and health systems (Vesinurm, 2025). Notably, a standardised methodological approach for patient-centred healthcare service modelling is still lacking (Cassidy et al., 2022).

Given the complex nature of healthcare processes and the importance of clear communication and planning, a standardised way of representation is required to both describe patient pathways and to understand the concepts (Bogale, Vesinurm, et al., 2024). A key challenge lies in developing a modelling approach that balances the precision required for machine execution with the simplicity needed for human comprehension (Ardito et al., 2020). From this perspective, machine-readable modelling can be seen as a requirement for properly leveraging EHR data.

There are various approaches that tackle the modelling of patient pathways, each with their unique focus and strengths. Analysing modelling languages from distinct traditions is essential for understanding how modelling approaches respond to the multifaceted nature of healthcare processes. Such variety is crucial for identifying how modelling languages can evolve towards more holistic representations of care. Therefore, this study focuses on the feasibility and usefulness of three different modelling languages: Unified Modelling Language (UML), Business Process Modelling Language (BPMN) and Customer Journey Modelling Language (CJML). UML, BPMN and CJML represent these contrasting paradigms, making them a relevant basis for this comparison.

There is no single representation method that would satisfy all the needs required in both complex patient pathways and health systems. For this reason, Cassidy et al. (2022) suggest using a combination of methods to address the limitations of individual approaches. The thesis focuses on kidney cancer as an illustrative example of a complex care process. It evaluates how UML, BPMN and CJML would capture key characteristics of this pathway and selects CJML for further development to enhance its support for patient journey modelling.

This study has three main aims. First, to deepen the understanding of how the care of long-term illnesses is organised by identifying the key characteristics relevant to modelling. Second, to assess whether these characteristics can be effectively represented as a patient journey aligned with healthcare system requirements. Third, to evaluate how CJML can be further improved to support this representation.

The research is guided by the following three research questions:

RQ1: What are the key characteristics of the kidney cancer care process from a process modelling perspective?
RQ2: How do UML, BPMN and CJML differ in their ability to represent the key characterises of a kidney cancer care process?
RQ3: How can CJML be developed to better support patient journey modelling in healthcare?

Through addressing these questions, the thesis aims to contribute to the development of a shared, interpretable modelling method. This should be suitable for diverse stakeholders, such as business analysts, healthcare and IT professionals (Bogale, Vesinurm, et al., 2024).

1.2 Research structure

This study consists of two main parts: a literature review and an empirical study. The literature review compiles current research and literature on kidney cancer treatment and patient process modelling. The empirical study investigates cancer treatment process and how its modelling can be performed using the chosen modelling language.

The empirical part of this master's thesis aims to answer research questions 1-3. The empirical study followed a design science research (DSR) process, which included workshops with healthcare professionals (HCPs), the development of an artefact, i.e. patient process models, and the collection and evaluation of expert feedback on the artefact. The purpose of the HCP workshops was to understand how the kidney cancer care process functions for cancer centre patients. The broader purpose of the workshops was to identify complexities in this care process and how modelling of such process could be performed with modelling languages. The analysis section revealed shortcomings in the chosen modelling language and gives suggestions for improvements which were lastly evaluated with experts researching healthcare organisations and modelling patient processes.

Modelling of the process focused on the typical phases of kidney cancer treatment and separately handled deviation situations. After the artefact was created, it was evaluated separately. Findings of this evaluation were analysed, discussed and incorporated to the development of the language. The aim of the modelling process was to create a structured representation of the patient pathway that would allow the identification of gaps in modelling and provide recommendations for improvements in the chosen modelling language. Alongside, inconsistencies in the treatment of kidney cancer were documented in this study.

This introductory section 1 builds the base of the thesis and the topic and is followed by section 2 provides review on the relevant literature from kidney cancer care and a deeper look into the modelling languages, their features and how the ones in focus have been used in the past. Section 3 presents the research methodology of this research. The analysis and created models are presented in section 4. The results are discussed in section 5, and lastly, section 6 concludes the study with a summary of its main findings.

2 Research methodology

This section explains the methodological choices and their constraints, literature review in part 2.1. and empirical study in part 2.2, including the chosen research methodology and methods for data collection and analysis. Lastly, 2.3 lists the ethical considerations.

2.1 Literature review

For the literature review, different research journal articles, conference papers and books were used as the primary sources. The search for relevant literature was conducted mainly through PubMed (NLM) database. In addition, Google Scholar and academic databases accessible via the University of Helsinki and Aalto University libraries were utilised to complement the primary search and to access materials not available through PubMed.

Search terms were based on core concepts relevant to the study, including combinations such as "*patient pathway modelling,*" "*care processes in chronic illness,*" "*healthcare operation management,*" "*complex patient pathway,*" *and* "*kidney/renal cancer care pathways*." These terms were refined based on preliminary search results to improve specificity and relevance.

In addition to peer-reviewed academic sources, publicly available websites were used to support the description of treatment methods and to enhance understanding of the kidney cancer care process. These included national healthcare portals such as hus.fi and kaikkisyovasta.fi, a site maintained by the Finnish Cancer Societies (fin. Syöpäjärjestöt), which provides accessible and up-to-date information about cancer care. These sources offered both general and case-specific insights into renal cancer treatment pathways and contributed to a more comprehensive understanding of national cancer care practices within the Finnish healthcare context.

Although the literature was not strictly limited by publication date, studies published within the last 20 years primarily chosen. Most of the included literature is from the last 10 years. This is beneficial due to the rapid development of the field and the increasingly critical state of healthcare systems, which demand up-to-date perspectives on patient process design and management of complex, chronic illnesses.

The selection of literature was based on both relevance to the research objectives and methodological reliability, with a particular focus on patient-centred and co-created care, process improvement and approaches applicable to help managing complex healthcare environments.

2.2 Empirical study

The empirical study followed a design science research (DSR) process, which included workshops, the development of an artefact, and the collection and evaluation of expert feedback on the artefact. This section provides an overview of the healthcare organisation, the applied DSR approach, and the data collection and analysis methods used.

2.2.1 Case description: Finnish healthcare system

Despite healthcare being a universal concept, this study's case focuses on the maintenance of health and production of health services in Finland. Many of the observations are still expandable and previous literature and experiences are gathered around the world. However, the features listed in this section are relevant to welfare state contexts.

Finland is a welfare state characterised by a high standard of living and relatively low poverty levels. While the healthcare system performs well in terms of overall effectiveness, its structure is notably fragmented (Keskimäki et al., 2023). Health financing is shared among several parties, municipalities, the national health insurance system, employers and households, each contributing a significant portion. This fragmented funding model extends to service provision as well, encompassing municipal, private and occupational healthcare systems. Consequently, coverage is uneven: although all residents are entitled to municipal health services, the availability and accessibility of care, especially primary care, can vary considerably between municipalities. Additionally, employed individuals have access to occupational health services, but the scope and quality of these services also differ depending on the employer.

The Hospital District of Helsinki and Uusimaa (HUS), is the largest producer of healthcare in Finland, employing 27,000 professionals and treating yearly nearly 750 000 patients annually (HUS, 2025c). HUS organises the specialised care in Uusimaa and oversees the nationally centralised care of many rare and severe diseases. This study focuses on The Comprehensive Cancer Centre at HUS, which is the largest and most versatile cancer treatment centre in Finland (HUS, 2025b). Cancer Centre's responsibilities include radiation therapy, cancer drug therapy, the treatment of blood diseases for patients over 16 in the Uusimaa region. Additionally, the Cancer Centre is responsible for breast surgery, special palliative and end-of-life care. As a university hospital, HUS also continuously develops and studies its processes and treatment methods.

Alongside the public, municipal healthcare system, Finland has additional significant producers, private and occupational health services (Keskimäki et al., 2023). The private sector largely focuses on non-emergency outpatient care, in both general and specialised cases, which is typically paid for by patients themselves or supported through insurance. Currently, only one private cancer hospital operates in Finland – Docrates by Mehiläinen. Occupational healthcare is a mandatory responsibility of employers, ensuring access to preventive and essential services for employees. In addition, university and other higher education students benefit from a dedicated, non-profit producer: the Finnish Student Health Service. HUS can receive referrals from each of them, and their care process differs slightly from that of those who have been treated from the beginning on the public side.

In addition to these, external producers have influence on the patient's care. In Finland, the Social Insurance Institution (Kela) provides reimbursement for prescription medication costs (Keskimäki et al., 2023). To access these subsidies, certain medications, particularly those for chronic or severe conditions, require a reimbursement approval from Kela based on the medical professional's application. This approval may be time-limited and subject to renewal. Without valid reimbursement status, patients are not eligible for subsidised prescription prices, which may significantly increase their out-of-pocket costs.

In this study, the term *producer* is used as an umbrella concept to describe all organisations involved in the production, coordination or delivery of healthcare services, regardless of their structural or operational model. While the term *provider* is more commonly used in healthcare literature to refer to entities that directly deliver care to patients, such as hospitals and healthcare professionals (HCPs), the concept of a producer better reflects the diversity of actors involved in the Finnish system as not all producers deliver care directly. For instance, organisations such as Kela or insurance companies influence patient care through financial mechanisms or service access policies but do not act as care providers. Therefore, all providers are producers, but not all producers are providers. This distinction is important in the context of process modelling, where different producers may have different roles, responsibilities and interfaces in the patient journey, despite not providing hands-on care.

2.2.2 Research process

This study requires researching the oncology of complex patient process and develop a model meeting its requirements. Building an artifact suits this purpose well and therefore, the empirical part of the study was conducted as design science research (DSR), an approach presented by Peffers et al. (2007)

and Hevner et al. (2004). The DSR process includes six steps: problem identification and motivation, definition of the objectives for a solution, design and development, demonstration, evaluation and communication. As Peffers et al. (2007) argue that the structured process of DSR is well-suited for developing and evaluating artefacts that address specific problems, it aligns well with the objectives of this study.

The choice of DSR as the research approach was further supported by Burwitz et al. (2013) who used the method for similar purpose. Their goal was to create a modelling language capable of addressing the requirements arising from the previously noted challenges in clinical pathways. The empirical part of this thesis focused primarily on a similar situation: the design and development phase highlighted the areas for further developing the modelling language. The design and development phases were also extended to the development of these points. Demonstration and evaluation phases were then performed for both the artefact and the development proposals.

The DSR process supports the creation of a solution for a unique need and context, combining knowledge derived directly out of the healthcare environment as well as existing literature. Figure 1 presents the research process of this study: the design science process phases guided the research process and multiple methods were used alongside. It shows how the research artifact is developed by integrating understanding from healthcare with existing knowledge from literature and prior studies. Then, models and proposals are iteratively evaluated through feedback and expert workshops.

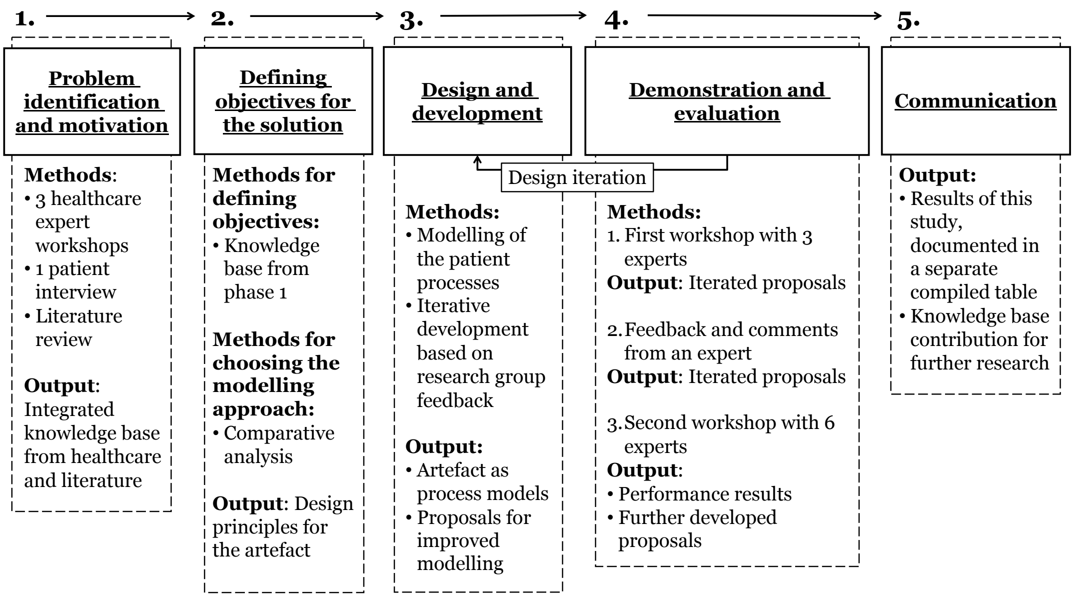


Figure 1 Research process, used methods and produced outputs

Evaluation of accuracy is considered from two perspectives: modelling language guidelines and the kidney cancer care process. Assessing the modelling language guidelines relates to quality requirements and depends on participants' understanding of these requirements. Therefore, accuracy evaluation in terms of modelling language guidelines was carried out iteratively during the design and development phase. The artifact's performance in representing the kidney cancer care process is evaluated in a separate phase dedicated to this assessment.

The research process defined in Figure 1 guided the study. In more detail, this led to the process being organised as follows:

1. Problem identification and motivation

Research started with workshops with HCPs working with kidney cancer patients and a literature review on the kidney cancer process and modelling techniques. The most important of practise rules in DSR is that the research must produce an "artifact created to address a problem" (Hevner et al., 2004, p. 82). This phase ensured that the research focused on addressing practical challenges in the use of modelling languages for complex patient pathways.

Workshops were organised to gain better insight of currently used patient pathways in kidney cancer care. A qualitative method is needed when trying to understand the phenomena in question. It is impossible to draw conclusions without involving experts from the field, those handling the situations daily. This type of data is not available for third parties and is affected by one's own experience and conception.

2. Defining objectives for a solution

After identifying the problem, objectives for a solution were defined. This second phase aims to determine what kind of an effect the design artefact should have on the defined problem (Peffers et al., 2007). Integrating new and existing knowledge on the problem and chosen modelling methodologies are done to establish a strong scientific foundation.

The literature review offered knowledge on patient process definitions, the typical kidney cancer care continuum and modelling possibilities. With understanding from the workshops, a process picture of typical kidney cancer care was created. Workshops provided elements of the actual kidney cancer care, which were able to include on top of the planned care process.

To further address known pain points, process modelling languages were evaluated based on insights from the workshops and the literature review. All three languages, Unified Modelling Language (UML), Business Process Modelling and Notation (BPMN) and Customer Journey Management Language (CJML), have been previously used for modelling patient processes and therefore chosen for this study. UML and BPMN are universally used and recommended options, and CJML represents a newer language.

3. Design and development

The third phase focuses on designing an artefact as a solution to the identified problem (Peffers et al., 2007). The design process was primarily based on the workshops, with the help of literature and modelling guidelines. Creating the artefact for the kidney cancer care process with either UML, BPMN or CJML was done to thoroughly test the artifact in the real-world application. This phase also aimed to test its strengths and weaknesses but also to highlight the complex nature of healthcare.

The model was also evaluated in the design and development phase but solely from the correctness aspect of quality. The development process was iterative, consisting of rounds evaluating the modelling choices and accuracy of the model.

4. Demonstration and evaluation

The demonstration and evaluation were performed simultaneously. This phase included two separate workshops both with their own impact on this study. Hevner et al. (2004) list that artefact can be evaluated, for example, in terms of accuracy, completeness, fit with the organisation, performance, reliability and usability, which all were listed as evaluated criteria in the workshop. The goal was to receive actionable proposals that combine both theoretical and practical contributions to further development of the artefact.

5. Communication

This study documents the research process, the problem, artefact and results of the demonstration and evaluation as requested Peffers et al. (2007). Hevner et al. (2004) defined as a communication guideline that “design science research must be presented effectively both to technology-oriented as well as management-oriented audiences” (p. 83). The researchers present at the demonstration and evaluation meet both requirements in the context of the study. Artefact building, key workshop findings and results are presented in section 4.

Lastly, “effective design-science research must provide clear and verifiable contributions in the areas of the design artifact” (Hevner et al., 2004, p. 83).

In accordance with the DSR guidelines, required improvements to the modelling language are recorded in a separate, comprehensive table.

2.2.3 Data collection methods

DSR requires iteration and evaluative processes which also require multiple rounds of data collection. In this study, the collection is was conducted as a series of workshops, structured by different means to suit the objectives. First round of workshops was performed in the Cancer Centre Department of the Helsinki University Hospital, and second with experts researching with healthcare organisations and patient journey modelling.

It is argued that “prescriptive knowledge created during the [DSR] build activity is assumed to have no truthlike value” (Iivari, 2007). This questions if the knowledge gained in the building process is worth to be accumulated. Sonnenberg and Vom Brocke (2012) studied this challenge and proposed that prescriptive knowledge can be achieved if DSR process follows three key principles. Their findings emphasise the importance of staged evaluations and iterative cycles to increase the design's truthfulness. In line with this, the present study applies the evaluation activities they recommend, assessing the artefact throughout the process and integrating insights from each iteration into the next.

1. First evaluation is gathered alongside the DSR stages 1 and 2, and as an output, justification for the problem, research gap and objectives are confirmed from both literature review and expert feedback.
2. Next round of evaluation is performed before the first prototype is built and the chosen modelling is confirmed by external researchers. Additionally, first iterations of the modelling are demonstrated shortly to the experts of the modelling language for validation on the accuracy and completeness.
3. Lastly, the created artefact is demonstrated to a different group of experts, working in a quasi-realistic setting as suggested, and comprehensive evaluation is gathered based on multiple criteria.
4. Validation in a realistic setting will remain to be performed but proposals for the developed modelling are documented in this study.

In total, the data collection and evaluation happen in DSR process stages 1 and 4. Also, stage 3 included evaluating discussions within the research group this study is a part of. These data collection and evaluation methods are presented in detail next.

2.2.3.1 Methods for problem identification and motivation

For problem identification and motivation, three workshops were conducted together with another researcher and involved kidney cancer experts to gain insights of the actual patient processes. One semi-structured interview was held with a kidney cancer patient to validate the expert information and bring forward patient experience. All of the discussions were held in Finnish.

HCP workshops

Expert workshops are the initial knowledge base of the empirical study. Only a very high-level picture of kidney cancer care path is available outside of the healthcare organisation as found in the literature review. The purpose of these workshops was to understand how the kidney cancer care process functions for cancer centre patients and how treatment and information flows in a care path process. The broader purpose was to identify complexities in this care process and how the outcomes of such process could be performed with modelling languages. This was targeted by dividing the workshop discussions into three sections:

1. Learn whether diagnosis and care plan follow a certain pathway, and how this pathway evolves.
2. Understand the kidney cancer patient pathway flows: which producers, alternatives and activities are included? What is required for smooth care and what points are leading to deviations?
3. Discover how patients are informed along the process.

Three separate HCP workshops were organised: one with a kidney cancer specialist KCS) and two with kidney cancer nurses. Participants were all familiar with each other as they worked closely together. Each workshop lasted from 60 to 90 minutes, allowing participants to engage at a comfortable pace. Participants were all from the Helsinki University Hospital's cancer centre located in Meilahti, Helsinki, Finland.

The HCPs were invited to participate to share their knowledge and were recruited by the hospital. The hospital chose participants based on their knowledge: who they saw as most potential and helpful. All participants were provided with a summary of the research beforehand. Workshops took place in participants' own reception rooms between April and May 2023. Workshops were audio recorded, with consent, so that they could be reanalysed if necessary. Each workshop began with signing a consent form and a brief introduction to the study and the motivation behind it.

Responsibilities were divided to two roles in all data collection workshops. The other researcher acted as the conversation leader and research assistant, the author of this study, was responsible for notetaking. This division helped both to focus on their own tasks . The conversation leader was able to lead the discussion based on the workshop template and react to HCP's comments. HCPs were given free word to tell their version of the current patient pathways. Alongside of modelling the patient pathway, the workshop aimed to cover other questions that are presented in the Appendix A.

The research assistant did not participate in the discussion other than to verify what has been said. She employed the structured note-taking process to capture the insights and suggestions of the participants. Different coloured notes were used to present different stakeholders, and interaction details between parties were written down on them. Post-it notes constructed a timeline of events on a larger base paper. This simple but effective notetaking method was chosen to already resemble the features of all studied modelling languages and to properly separate every notable action and communication point. An example of notes for the start of treatment is shown in Figure 2.

Figure 2 Example of the notes from the start of treatment

Patient interview

Patient perspective on this study is gathered in only one patient discussion which was performed as a semi-structured interview. Their participation was also entirely voluntary. After introduction to the study and defining the background information and cancer status, the patient was encouraged to speak freely about their treatment process and experience. The interviewer occasionally guided the discussion towards topics relevant to the study and asked follow-up questions to clarify specific points. These questions are listed in Appendix B.

Participant backgrounds

Backgrounds of the participants are shortly introduced next. The first workshop included oncology specialist that had treated primarily kidney cancer cases since January 2022, so they had one year of experience in proper tasks. They handled prostate cancer referrals and, together with another specialist, were responsible for almost all patients in the cancer centre. They had also participated in weekly common cancer meetings that deal with cases in which the form of treatment was not clear.

Second workshop included a nurse from cancer centre, having worked with cancers for 11 years and since 2017 especially with urological cancers. They had experience on the cytostatic care and was at the time of the workshop working on the reception side. The third and last workshop also included a nurse from cancer centre, having a long career in the cancer centre but the actual experience years remained unknown. Their workshop was conducted remotely but it worked in the same way as the previous ones.

The patient participating in the study had been suffering from cancer for several years and their condition had fluctuated over the years. At the time of the interview, their cancer had been diagnosed as incurable a short time earlier. They therefore had visibility into several stages of kidney cancer treatment.

The background information and lengths of the discussions are listed in Table 1.

Table 1 Backgrounds of the participating HCPs and cancer patient

Role	Type	Experience	Length
Oncology specialist	Workshop	Special experience of 1 year, 3 months	1h 30 min
Nurse at the cancer centre	Workshop	11 years with cancers, since 2017 especially with urological cancers	1h 30 min
Nurse at the cancer centre	Workshop	Multiple years	1h 06 min
Patient	Semi-structured interview	Evolving kidney cancer for 6 years, recently diagnosed as chronic	1h 12 min

2.2.3.2 Methods for demonstration and evaluation

Following the design science methodology, the created artefact, patient process models, require both demonstration and evaluation. The models and proposals for future improvement were reviewed in two separate evaluation sessions with experts. The models and proposed improvements were further developed between these sessions, applying learnings from the first sessions to the models to drive further development in the second. Alongside, also feedback from the creator of the modelling language was gathered to validate the information in this study.

The first workshop acted as a pilot version for the latter one, including a small group of experts researching the healthcare organisations. This workshop required showcasing both the patient process models, as most of the participant were not familiar with process modelling. Their expertise on phenomena in the healthcare organisations was beneficial for the theoretical contribution of the proposed improvements.

The second, larger workshop included researchers especially familiar with the modelling of patient processes. The second demonstration therefore aimed to present the usefulness of proposed improvements in the patient process modelling. Their expertise on process modelling in the healthcare organisations was beneficial for the practical contribution of the proposed improvements.

Depending on the proposed improvement, the assessment was performed by evaluating the following qualities depicted by Hevner et al. (2004): accuracy, clarity, fit with the organisation, reliability, usability and completeness. The evaluation sought to gain an understanding of these by following the framework in Table 2.

Participating experts were given the opportunity to provide their insights especially on the improvements and suggest any modifications necessary to enhance these predefined criteria. To ease the evaluation, each of the criteria was modified to make them slightly more memorable:

- Accurate
- Clear
- Benefits the user
- Reliable
- Common Need (Usability)
- Ease of Use (Usability)
- Relevant aspect missing from CJML (Completeness)

Table 2 Framework for the evaluated qualities

Evaluated dimension	Questions guiding the evaluation
Accuracy	Does the proposed extension enable more precise or correct representation of processes?
Clarity	Does this enhance the visual clarity and comprehensibility of CJML models?
User Benefit / Organisational Fit	Does this improve the user experience? Does it add practical value for actual use? How well does this align with the modelling needs of healthcare?
Reliability	Will the feature behave predictably and consistently across cases?
Usability	Is this a common need? Is it easy and intuitive for modelers and stakeholders to adopt and use?
Completeness	Does it help model relevant aspects that are currently missing and identified in this study?

Next, the structure of demonstration and evaluation workshops is presented in more detail and methods for feedback gathering are opened.

Evaluation workshop 1

The participating experts were invited due to their knowledge of healthcare operation management and ability to connect the findings to real-life healthcare organisation settings. Experience background in summarised below in Table 3. The workshop was held in Finnish as all participants were native Finnish speakers. Two out of the three participants were not particularly familiar with CJML or modelling languages, so this session worked as a pilot, primary evaluation. Therefore, the demonstration also required a short summary of CJML's core elements and qualities. The evaluation session was held as a workshop. All materials were printed to provide easy step-by-step demonstration, and each participant had the possibility to investigate the models as they liked. The workshop lasted 1 h 40 minutes in total.

The demonstrated material included the modelled kidney cancer journeys and supplementary models of special cases (see Appendix C). For the proposed improvements, the author presented the current visualisations and versions with improvements. For instance, the decision point was demonstrated as the simplified version (as in Figure 12, p. 75), and the evaluation team was given proposals for separate inclusive and exclusive modelling of the decision point. The evaluation was therefore carried out by comparing the current modelling with proposals of different levels of detail. All proposed improvement options can be found in Appendix D.

Table 3 Participant experience in evaluation workshop 1

Participant	Experience	Length
1	Nearly one year of research experience in patient journey efficiency and care continuity	1h 40 min
2	2 years of research experience in integrated care and improving management of patients with multimorbidity, also with a focus on how existing different systems contribute to the disruptions in care coordination and service delivery	
3	4 years of research experience in the management of complex patient journeys, also knowledge in modelling languages	

The workshop discussion flowed organically, and the author decided not to manage it too rigorously to allow the emergence of other possible improvement opportunities. Necessary clarifications were made if the qualities had not already emerged in the discussion. Demonstration and evaluation happened partially simultaneously: when evaluated qualities emerged in the demonstrated kidney cancer models and discussion revolving around them, proposed improvements were presented case by case to evaluate each in their relevant setting. For instance, the example of complex care path modelling (Figure 12, p. 75) and its related improvements were evaluated profoundly all together.

Lastly, all proposed improvements were presented in a comprehensive table. In addition to the discussion, all participants were asked to mark the ones they evaluated as primarily important and which ones are second priority. Each were identified by marking '+' for primary important and '(+)' for second priority.

Feedback on CJML usage

In between the workshops, the developer of CJML provided feedback on the proposals, mainly for validation of uncertainties. Their contribution in this round included written comments on the study, defining the used terminology and validating assumptions with regard to visual notations.

Evaluation workshop 2

The primary evaluation workshop was organised to validate and refine proposed improvements to the CJML. The workshop was held as remotely and everyone participated from their own device. In contrary to the previous workshops, this workshop was held in English as the participants were non-Finnish speakers. The aim was to critically evaluate each feature from both conceptual and practical modelling perspectives.

The session brought together six participants with varying degrees of experience with CJML, ranging from under a year to over 15 years. The group included the researcher overseeing the development of CJML, members of the research team involved in its development, and other experts with recent hands-on experience of CJML, from cases such as actual care journeys and depicting information flows. Experience background in summarised below in Table 4.

Table 4 Participant experience in evaluation workshop 2

Participant	Experience	Length
1	Less than a year of experience in modelling customer journeys from patient perspective and trying to predict the experience from data	1h 49 min
2	2 years of research experience in technical aspect in journey modelling, previously experienced in CJML modelling and using databases to mine customer journeys	
3	Over 1,5 years of research experience in longitudinal studies on patient pathways	
4	Multiple years of experience in digital health research, most recently from visual modelling of patient pathways to improve its description and communication	
5	2 years of relevant research experience, recently modelled patient-centred CJML pathways	
6	15 years of research experience from human-computer interaction to service innovation and modelling of patient pathways, recently focused in practical and theoretical aspects of service innovation and user modelling. Overseeing the work on CJML	

The workshop was guided by the following structure:

1. Introduction and objectives (15 minutes)

The session began with a brief personal introduction and an invitation for participants to share their background. It was confirmed that all attendees had some previous experience with CJML. The objectives of the workshop were then outlined:

- To provide context for the development proposals, which were based on findings from initial workshops with HCPs and modelling of the kidney cancer patient journey
- To collaboratively evaluate each proposal, identify strengths and weaknesses, prioritise the most valuable features and suggest refinements
- To use an online voting to collect structured feedback on each proposal based on pre-defined criteria
- To complete the core agenda in time

2. Structured evaluation process

All proposals were first presented briefly using a summary slide including names and icons. Each proposal was then discussed individually, beginning with those that were either prioritised in the pilot workshop or already known to include unclear elements.

The author introduced the rationale behind each proposal, how it had been developed and what problem it aimed to address. Then, participants were encouraged to reflect on their relevance, share past experiences and suggest alternative solutions or further refinements. Contributions focused not only on theoretical modelling value but also on practical usability in real-world contexts. For each proposal, participants were asked additional questions, such as:

- Is this addition necessary or something identified before?
- How might it be visually represented most effectively?
- What could be improved?

Each proposal was evaluated using a two-step framework, with votes collected immediately after the discussion of the proposal.

Step 1: Evaluation criteria

Participants were introduced to seven evaluation criteria presented in the previous Table 2 on page 28. After the proposal was discussed, participants voted on whether it fulfilled each of the criteria.

Step 2: Implementation readiness

Alongside these criteria, participants also voted on the overall readiness of the proposals using the following options:

- **Useful and ready for further development**: The proposal is clearly beneficial and can be taken forward as-is or with minor refinement.
- **Promising but needs iteration**: There is potential value, but it requires further development, clarification or testing.
- **Not currently relevant or beneficial**: The idea does not offer clear added value or does not align with current modelling needs.

3. Final Prioritisation

At the end of the workshop, participants were asked to allocate multiple votes to the proposals they considered most valuable overall. In addition, they were asked to rank them in order of priority, with no tied positions allowed. This helped to surface the features perceived as most impactful for future development.

2.2.4 Data analysis

Mapping of insights was performed right after the workshops with the HCPs. All workshops were recorded with permission and the one held online had automatic transcription on. The insights and information shared during the sessions were first transformed into digital format using Microsoft PowerPoint and the timeline was made coherent. This presentation, that was not correctly modelled with any of the languages, was first evaluated with the research group and then fact checked with recordings by note-taker before transforming the data into a process model. This step was taken to minimize doing useless work and errors.

After the first pathway iteration, critical points and elements of the patient pathway were identified. When comparing the applicability of UML, BPMN, and CJML several aspects had to be considered in order to determine which modeling language is most suitable. Each process language was first thoroughly researched, and an effort was made to understand the characteristics of each. After CJML was chosen for the artefact, it was iteratively built again in Microsoft PowerPoint with the official visual element, evaluated, refined, approved within the research group and validated with the developer of CJML.

2.3 Ethical considerations

The research was conducted as a master's thesis and its data collection was jointly conducted with a researcher working in Aalto University School of Science, Department of Industrial Engineering and Management as part of the PATHWAY project. The research herein has received an ethical approval of the Aalto University Research Ethics Committee (Decision D/662/03.04/2022) and research permit (13/2023) from the Helsinki University Hospital.

Aalto University's connections to HUS allowed the research collaboration. The research output is currently intended for research purposes, although the final target organisations are healthcare producers. Received knowledge and experience from the professionals of HUS was highly relevant to achieving the goals of this study.

The only personal data collected from the workshops were names and work titles. Only work title was recorder and personal information were required to fill in the consent form. This data and workshop recordings that could be used to identify the participants were stored in secure platforms owned by Aalto University. The raw data, workshop recordings, were only stored for the duration of the research.

3 Literature review

The theoretical part of the study begins with definitions and the nature of the study (3.1). This is followed by a short overview of the kidney cancer (3.2) and a deeper look at its care process in part (3.3). Part (3.4) provides a literature overview of the studied process modelling languages, their features and why these three have been explicitly chosen for this study. Lastly, a summary of the review is given in part (3.5).

3.1 Patient pathways

Patient pathways represent the sequence of services and care patients receive throughout their treatment journey (Vesinurm, Sylgren, et al., 2024). The use of *patient* pathways emerged as a critical concept in addressing the challenges associated with delivering coherent and sustainable healthcare services (Panella et al., 2003). The benefits of effectively managing patient pathways have been acknowledged at least since the 1980's (Chu & Cesnik, 1998). Simultaneously, clinical guidelines (CGs) have been in use as a standard approach to managing medical activities (Tehrani et al., 2013). CGs serve as structured, multidisciplinary care plans outlining diagnostic and therapeutic interventions for specific medical cases (Tehrani et al., 2013). The patient pathway, serves as the service production plan for a specific type of patient from the beginning, whereas the CGs are subsequently customised for individual cases (Vesinurm, Sylgren, et al., 2024).

The term *pathway* is a crucial aspect of planned healthcare processes. Generally, pathways are seen as structuring (or restructuring) care by introducing standardisation into the process, which reduces variability and increases clarity around how care is delivered (Vanhaecht et al., 2009). Various definitions of pathways in healthcare exist, and terms such as clinical pathways and care pathways have been commonly used for the purpose in the past (Campbell et al., 1998). While all patients follow a specific care process, some are also guided by a clinical pathway (Vanhaecht et al., 2009) - structured sets of medical interventions informed either in diagnosis or by clinical expertise, such as in CGs (Vesinurm, 2025). In contrast, care pathways build upon clinical pathways incorporating additional elements that facilitate care delivery, such as scheduling and coordination (Olsson et al., 2009), but also by advocating the patient expectations and facilitating the sufficient communication (Schrijvers et al., 2012). For example, integrating telemedicine solutions were cases where some form of care pathway creation was needed to design the changes from the face-to-face connection to remote (Schrijvers et al., 2012). Consequently, patient pathways can be understood as a combination of both approaches (Eklund et al., 2024; Vesinurm, Sylgren, et al., 2024): it's "the service production plan for a type of patients which is then applied and modified for individual cases" (Vesinurm, 2025, p. 23).

In recent years, emphasis has been on *customer-centric* pathways, although customer centrality itself has been acknowledged in providing services for a long period (Gustafsson & Johnson, 2003). Cassidy et al. (2022) emphasise having the patient's viewpoint within the primary clinical activities to establish a comprehension of the patient-centric pathway as a complete entity.

In Finland, patient pathways are found in use for structuring care and enhancing coordination among healthcare professionals. However, a broader exploration is still needed to enhance the accessibility and timeliness of the pathways, and to acknowledge the missing incorporation with the patient and their families (Eklund et al., 2024). Despite the recognised benefits of using pathways and the general emphasis on patient needs and family involvement, individuals with multiple chronic conditions often do not receive genuinely patient-centred care (Haywood et al., 2006). Patient-centredness continues to be a key feature for improved health outcomes (Vanhaecht et al., 2009) and cost-effectiveness (Olsson et al., 2009; Schrijvers et al., 2012).

The definition of customer and patient *journeys* is broadening the scope of pathways and is seen as reflecting an individual's experience of following those pathways (Bogale, Vesinurm, et al., 2024). The patient pathway outlines the planned course of care, what should happen, when and by whom. The journey approach additionally captures the experiences that the patient goes through during the care process (Manchaiah et al., 2011).

In service design, studies using customer journey approaches might face incoherence in terminology but it typically modifies the process from the beginning based on customers' behaviour and experiences (Følstad & Kvale, 2018). This means that the patient journey is especially taking into account the primary aspects of healthcare: the patient's medical condition, functionality, experience and emotions (Oben, 2020). From the other point of view, the patient pathway will transform into a patient journey when modifying it to the patient and moving from planned to actual care (Vesinurm, Sylgren, et al., 2024).

The dual perspective (i.e. including both healthcare professionals and patients) of patient pathway and journey both reinforces shared insights and reveals critical differences, offering a more comprehensive understanding than either perspective alone (Larsen et al., 2024). The patient journey approach can help to identify crucial points in communication and care disruptions, such as misdiagnosis (Vesinurm, Dunweber, et al., 2024). Journey approach can help identifying factors affecting care, such as patient dissatisfaction deteriorating the quality of care.

Haywood et al. (2006) argue that the benefits of using patient journey approaches are not limited to recognising shortcomings or increasing patient satisfaction, despite these being some of the most measured outcomes. They continue to argue that it could also lead to identifying missed opportunities, such as building the patient–provider relationship that has been found beneficial in providing better care. This is related to the concept of value co-creation of health (Laukka et al., 2025) that is seen as an essential part of patient journeys.

The co-creation of health is also seen as a supporting quality for creating more patient-centred care (World Health Assembly, 2016). Elements of co-creation are included on multiple occasions, including active participation in decision-making, engaging with clinical staff and fellow patients, following medical recommendations and independently seeking relevant information (Danaher et al., 2024). Although the literature is limited in evaluating value co-creation in healthcare, it's noted as beneficial for customer satisfaction in service interactions (Gallan et al., 2013). The journey approach is therefore considered for this study as it's aligned with the qualities of both planned and actual pathways that are evaluated in the case of kidney cancer care.

3.1.1 Complex patient journeys

Characterising complex care is in itself complex and consists of multiple aspects. "The development and application of clinical guidelines, the care of a patient with multiple clinical and social needs, and the coordination of educational and development initiatives throughout a practice or department are all issues that lie in the zone of complexity (Plsek & Greenhalgh, 2001, p. 627). For instance, complex patients can be seen as those whose care journeys involve frequent non-standard decisions and are marked by considerable uncertainty throughout the process and its outcomes (Vesinurm, 2025). However, there is no single definition that describes complexity as a whole. Therefore, this section presents factors that influence the complexity in patient journeys.

Taplin et al. (2012) identify cancer care as a good example for examining such complex healthcare processes as it encompasses the full spectrum of healthcare concerns and the care continuum, with distinct stages but different focus points and needs. Diseases requiring specialised care involve countless small steps taken by both patients and producers, each step connecting to others through exchanges of information and responsibility (Taplin &

Rodgers, 2010). The presence of multiple producers and institutions across various phases further intensifies the complexity of such care.

This dual complexity (Seys et al., 2019), stemming from both the nature of the disease and the fragmented care environment, can result in treatment that feels unpredictable, inconsistent and fragmented, resembling the behaviour of complex adaptive systems (Plsek & Greenhalgh, 2001; Resnicow & Page, 2008). The management of such complex patient journeys can lead to failures in care that are addressed in this study as patient journey disruptions (PJDs) (Vesinurm, Sylgren, et al., 2024). PJDs are defined as deviating the patient journey from the expected and are seen as particularly relevant in the context of chronic illness, where the complexity of patient processes often leads to unexpected or non-linear trajectories.

Another factor that has a significant impact on the complexity of a chronic patient's care is the continuity, or especially its discontinuity. Discontinuities in care can arise from various causes, including challenges in care delivery, process management, digitalisation, as well as patient's own psychological factors and life circumstances (Vehkamaki et al., 2024).

Vesinurm (2025) listed special qualities and complexities deeply rooted in healthcare services and managing of complex patient journeys that differentiate their handling compared to other services. The complexity-enhancing features of these six areas are as follows:

Uniquely formed demand: According to Vesinurm (2025), unlike many other services, the formation of demand in healthcare is not solely driven by the presence of a need. For instance, external financial factors and individuals' reluctance to seek care may prevent real medical needs from converting into actual service demand. This mismatch between care needs and service demand is also further discussed by Vehkamaki et al. (2024). Moreover, there is also demand for 'help' without a medical basis (Lillrank, 2018), which poses challenges in allocating appropriate resources. Vesinurm (2025) highlights this complexity as especially relevant in publicly funded systems that aim to identify and respond to unmet needs early.

Uncertainty in outcomes: Patient journeys vary in how closely they follow care plans due to individual differences, uncertainties in care and the inherent complexities of healthcare (Vesinurm, Sylgren, et al., 2024). The challenges of managing medical activities by clinical guidelines (CGs) are mostly apparent in complex healthcare settings where processes are less structured and consists of a network of multiple care providers (Mould et al., 2010). However, the outcomes of patient pathways are not just the results of medical interventions but also outcomes of natural disease progression, placebo/nocebo effects, and lifestyle or behavioural changes (Lillrank, 2018). These factors introduce significant uncertainty and variability in the process outcomes.

Co-creation: The patient plays an active role in managing their care, complying with treatment and making decisions jointly with healthcare professionals. Co-creation of health requires properly defining the roles and responsibilities of all participating actors for different scenarios to, e.g., define what the patient is responsible for and expected to do (Vesinurm, 2025).

Information asymmetry: Healthcare processes are heavily dependent on both information and knowledge. As Di Ciccio et al. (2015) note, such knowledge-intensive processes depend heavily on human expertise to navigate interrelated decisions. When the patient is included in this context, the inherent information asymmetry often becomes apparent: patients may struggle to understand the rationale behind different care options, their potential impact on health outcomes, or conversely, how these choices influence the overall cost of care (Vesinurm, 2025).

Open system dynamics: Patient conditions and needs can change unpredictably, or they could drop out of care entirely. Contrary to closed systems where inputs and outputs are more controlled, managing patient journeys as open healthcare systems must acknowledge the uncontrollable externalities which complicate the system even further (Vesinurm, 2025).

Obligations of public mission: Public healthcare systems are subject to both financial limitations and policy obligations. They are governed by ethics, laws and the obligation to treat each patient according to their care needs, no matter how complex and multi-problematic they may be (Vesinurm, 2025).

Improving the care within complex healthcare has been approached through various proposals. According to Zapka et al. (2003), the focus of care processes used to largely be on the types of care, but finding shortcomings in the transitions between the different care phases is equally important. Responsibility for care and outcomes is shared among all the stakeholders (Curry, 2000) but the question is how each of them can contribute to care that improves overall outcomes (Hiatt & Rimer, 1999) and reduces shortcomings. Anhang Price et al. (2010) and Zapka et al. (2003) identify care interfaces, points at which information and responsibility are handed off between different stakeholders—as crucial moments in the care process that present significant opportunities for improvement.

Zerbato et al. (2015) add that integrating healthcare processes with consistent and reliable data sources is essential for improving medical performance and supporting decision-making activities. These tasks often require specialised support for management and execution, and as such the management of patient pathways also requires a complex, multi-step process. A patient-centred care plan allows patients to take an active role in managing their own care (Halvorsrud, Kvale, et al., 2016) and can thus be seen as a supporting factor for the care organiser.

Medical knowledge is recorded in CGs, giving recommendations for patient care and also aiming for consistency and reduction of errors (Barth et al., 2016). However, multiple internal and external barriers are shown to contribute to the failure of clinicians not following these guidelines. In a complex care dynamic, errors in patient care are seen as a result of poorly designed systems rather than incompetent care providers (Ash et al., 2004), which underlines the improvement needed at the process management level. CGs are often seen as overly rigid and unable to accommodate human discretion, often failing in situations where decisions rely solely on clinical judgment (Tehrani et al., 2013). In general, joining the medical knowledge and clinical judgement with patient's preferences in the treatment decisions are seen as providing the highest continuum of care engagement (Carman et al., 2013).

Process models can help in describing the patient journeys, accordingly, integrating medical knowledge in CGs but also highlighting the concepts that affect the care, especially multiple communication and decision dependencies (Bogale, Vesinurm, et al., 2024). However, the modelling of *complex* patient journeys requires clearer definitions to match the requirements. Firstly, the modelling requires a clear process design and development, a patient-centred approach and needs to match the requirements of clinical decisions (Burwitz et al., 2013). Secondly, it should acknowledge the unique qualities of healthcare, which increase complexity. However, current process modelling approaches are developed for services that differ from the healthcare settings, which is a complex and unique service type, and in turn, fail to meet the requirements of healthcare.

3.2 Kidney cancer

Kidney cancer, also known as renal cancer, is an umbrella term for cancers usually originating in the epithelial cells of the renal tubule (Kaikki syövästä, 2025c). Malignant kidney tumours represent 2% of the global cancer burden, with incidence rates steadily increasing as large age groups get older (Turajlic et al., 2018). The epidemiology of renal cancer is largely unknown. Incidence rates of kidney cancer rise with age and the typical time of diagnosis is between the ages of 60 and 70 (Kaikki syövästä, 2025c). For unexplainable reasons, incidence is twice as high in men compared with women, but studies suggest that factors beyond sociocultural habits and health behaviours contribute to this gender disparity (Scelo et al., 2018). Despite the disparity, especially tobacco and obesity are viewed as establishing risk factors (Kaikki syövästä, 2025c; Scelo & Larose, 2018).

Renal cancer comprises multiple histological subtypes, each defined by distinct molecular characteristics (Turajlic et al., 2018). The most common forms of kidney cancer include renal cell carcinoma (RCC), transitional cell carcinoma (TCC), and Wilms' tumour. Among these, clear cell renal cell carcinoma (ccRCC) is the predominant subtype of RCC, representing approximately 75% of all kidney cancer diagnoses (Moch et al., 2016).

Staging in cancer care refers to assessing how large the initial tumour is and determining how far the disease has spread (Swami et al., 2019). Kidney cancer is staged using the tumour-node-metastasis (TNM) system developed by the American Joint Committee on Cancer (AJCC), which is the most widely adopted and universally recognised method for cancer staging. Cancers detected at an early stage (Stage I) usually have a good outlook. Although later-stage (II-IV) cancers tend to be more developed, they can still often be managed effectively with appropriate treatment (Swami et al., 2019). Staging plays a critical role in predicting patient prognosis, informing treatment and management decisions, and shaping the follow-up and surveillance plans.

Once cancer has been diagnosed, treatment follows a care plan that is curated for each individual. The renal cancer care pathway at HUS is represented in four stages: “From Symptoms to Diagnosis”, “Getting a Diagnosis”, “Treatments” and “After Treatments” (HUS, 2025a). This care process is a set of interactions and actions that occur within and between healthcare providers, organisations and patients throughout the different phases of the cancer care continuum.

The life expectancy of kidney cancer patients differs drastically between stages of cancer. For instance, the survival rate of ccRCC in stages I-III is high, but the outlook for patients with widespread ccRCC is significantly poorer, with fewer than 10% surviving beyond five years after diagnosis (Turajlic et al., 2018). Generally, about 70% of treated patients are alive after 5 years after which surveillance ends at HUS if no reoccurrence has appeared. In cases where treatment is ineffective and there are no signs of improvement, patients are offered end-of-life care for the rest of their life.

3.3 The kidney cancer care process

This section opens the processes of care within the different segments of care across the Cancer Care Continuum implemented by Taplin et al. (2012). The Cancer Care Continuum aligns with the renal cancer care pathway available at HUS and describes the approach of delivering consistent, coordinated care to a kidney cancer patient over time and across various stages of care. As neither the renal cancer care pathway nor the empirical part of the study includes the stages prior to the detection of cancer, the review is narrowed to five types of care: detection, diagnosis, treatment, post-treatment survivorship and end-of-life care. All five are briefly discussed and transitions within and between them are highlighted. Although the emphasis is on kidney cancer, certain elements of typical cancer care are also included to emphasise the nature of complex care processes.

3.3.1 Detection

Zapka et al. (2003) present moving from detection to diagnosis as a two-step process: (1) detecting cancer or its precursors in asymptomatic or symptomatic patients, followed by (2) a diagnostic evaluation of an abnormal test result, these two being strongly intertwined.

Typically, cancer is found when a patient notices a new symptom and seeks medical attention, generally from primary healthcare. For instance, gastrointestinal tumours are often associated with indigestion, pain and blood in the stool. Blood urine tests should always be done to rule out tumours of the urinary tract organs. General symptoms such as weight loss and abnormal fatigue may also indicate cancer. Detecting an abnormality in the consultation leads to follow-ups to diagnose the causes. This requires additional examinations that are booked separately for the patient.

According to HUS (2025a), the usual primary care tests for suspected kidney cancer are a urine sample and blood tests. Nowadays, a large proportion of kidney cancers are discovered by chance during an ultrasound or Computed Tomography (CT) scan for another reason and only a small proportion of kidney cancers are found on the basis of classic symptoms (Jayson & Sanders, 1998). However, cancers found by chance are usually not yet in metastasis (i.e., not spread to other parts of the body, >75% of cases) (Kaikki syövästä, 2025c) which has affected the mortality rates of kidney cancer. If abnormalities are detected, the physician will refer the patient from primary healthcare to HUS. Detection is a sensitive point for varying care: it typically requires multiple additional days and three or more prereferral consultations for women to receive a kidney cancer referral compared to men (Lyratzopoulos et al., 2013).

Kidney cancer can be considered an insidious disease as it often progresses without significant symptoms, and the tumour is very susceptible to spreading to the lungs, including through the bloodstream. According to Kaikki syövästä (2025c), the classic symptoms of kidney cancer, haematuria, flank pain and a mass, are indicative that the cancer has already spread outside the kidney. In the early stages, symptoms are often non-existent making the disease difficult to treat. More commonly, kidney cancer is found with patients who come to the doctor for vague symptoms such as fatigue, loss of appetite, fever and weight loss.

3.3.2 Diagnosis

Diagnosis follows detection (Zapka et al., 2003) and examines abnormal test results: it is characterised by repeated steps and a combination of multiple testing methods, with each test providing a varying level of information about the abnormality. The process is not linear, and several tests are often required before an accurate and reliable diagnosis is achieved.

Diagnosis is driven by observations that are based on test results from various experiments and the decision-making done by medical specialists (Pufahl et al., 2022). Lenz and Reichert (2007) referred to this as a diagnostic–therapeutic cycle: medical experts use patient-related information and existing medical knowledge as inputs for their decision-making. Existing medical knowledge is usually captured in CGs, however these have no capability to handle human judgement (Barth et al., 2016). Therefore, a process leading to diagnosis is triggered from the results of multiple decisions, ones made by both humans and systems recommending or excluding alternatives.

Methods for diagnosis are diverse. The following techniques are typically used in the case of kidney cancer: imaging, endoscopy, cell and tissue sample and laboratory tests. Most tumours can be classified as benign or malignant with CT scans but the most reliable information about the tumour is found with a biopsy. These identifications then lead to diagnoses of either precancerous conditions or cancer. Appointments with physicians and nurses include reviewing the situation, examinations and treatment planning. Additionally, nurses provide patients with additional information on the practicalities and offer supportive therapies.

Next, the testing methods used in diagnosis are presented in more detail.

Imaging is usually performed as a combination of techniques to provide sufficient information on the symptoms, for visualising and locating the possible tumour with methods that are selected based on the type and expected location of the abnormality. CT scan is the most used method to detect cancer and its spread. It's common for imaging the chest and abdominal cavity, urinary tract organs and gynaecological cancers. It is based on the use of X-rays and provides an image with relatively accurate anatomical structure. Ultrasound is used for the initial diagnosis of tumours, for example for gynaecological organs, abdominal cavity and kidney tumours, and to rule out metastases in the liver. The ultrasound scan does not cause radiation exposure. Nuclear medicine scans use radioactive tracers that target the organ being examined. Imaging techniques locate the tracker and determine where the cancer has spread.

An endoscopy test looks inside the body, typically examining the gastrointestinal tract, bronchi, bladder, uterus, prostate or the head and neck area. An endoscopy allows a visual inspection of the tumour through an endoscope, providing precise information about the appearance, size and location of the tumour.

Tests on cell and tissue samples involve tumour typing based on histological examination of the cancer tissue, where the tissue sample is stained and analysed at the cellular level using a microscope A biopsy is always taken from the tumour to confirm the diagnosis and determine the most appropriate treatment for each patient. The final cancer diagnosis is typically done based on a pathologist's tissue sample biopsy report. Besides defining the type of tumour, a pathologist can also determine, for example, its rate of cell division or hormone dependence. The latter helps determine whether the patient is likely to benefit from hormonal therapy, for example in case of breast cancer.

Laboratory tests, typically **blood tests**, can be taken at the stage when cancer is only suspected. The results of a laboratory tests can be normal, but in case the cancer has spread and changed the function of an organ, blood tests almost invariably appear abnormal. For certain cancers, blood tests are used to check for the body's own biomarkers, e.g. certain proteins produced by tumour cells. The levels of tumour markers in the bloodstream vary depending on the activity of the cancer. As a part of the treatment after a confirmed diagnosis, laboratory tests before and during treatment are used to assess the function of different organs and recovery from harsh treatments.

3.3.3 Treatment

The cancer treatment phase follows a care plan curated to the patient. The choice of treatment methods depends on multiple factors, such as the type and form of cancer, the extent of cancer spread and the patient's overall health and age. Taplin et al. (2012) list three methods for cancer treatment: surgery, radiation, chemotherapy, or some combination of them. The Cancer Society of Finland add hormone therapy, immunotherapy and targeted drugs as possible treatment methods (Kaikki syövästä, 2025f). For the treatment of kidney cancer specifically, the three above mentioned methods represent first line treatments, but literature indicates that several other approaches have been used and are currently under active investigation. The most common approaches are described in more detail below.

Surgery as a treatment method is considered the first option of treatment in many cases as it performs well at an early stage of cancer (Kaikki syövästä, 2025g). It is also the primary treatment method for renal cancer tumours that have not metastasised (HUS, 2025a). It's typically performed as keyhole surgery under general anaesthesia and does not require medication in addition to the surgery. Combination of therapies is required if the cancer tumour has shed cancer cells to other parts of the body or if the tumour is in such a challenging location that it cannot be operated at all. Most stage IV tumours are inoperable and involve other forms of treatment.

Radiotherapy uses radiation to destroy cancer cells and shrink tumours (Kaikki syövästä, 2025d). Cancer cells typically divide faster than normal tissue, making them particularly sensitive to radiotherapy. Radiotherapy can be performed externally with a radiotherapy device or internally by introducing a radiation source into the body, e.g. in radionuclide therapy. Radiotherapy is completely painless, and while side effects are possible, most people can live a relatively normal life during treatment. Radiotherapy is usually given over a period of 2-8 weeks. For treating kidney cancer, radiation therapy is generally ineffective, except for palliating pain caused by bone metastases (Fossa et al., 1982).

Chemotherapy uses cytotoxic drugs for targeting the rapidly dividing cancer cells but simultaneously, these cytostatics affect all dividing cells, including healthy tissue (Kaikki syövästä, 2025e). For this reason, the pace of care is planned so that normal tissue has time to recover, and cancer cells do not. As reported in the Urologic Diseases in America project (Wallen et al., 2007), although recent clinical trials in chemotherapy have demonstrated some potential in treating kidney cancer, it has mainly shown limited effectiveness.

Hormone therapy is considered as precision medicine targeting the growth of cancer cells by blocking their ability to exploit the body's hormones (Kaikki syövästä, 2025a). The treatment is used for cancers where hormones strongly regulate the normal growth and development of the organs, e.g. breast cancer and prostate cancer. The human body tolerates hormone therapy better compared to chemotherapy and thus, the treatment is generally continued for long periods of time, usually years.

Immunotherapy is given together with chemotherapy as a combination treatment (Kaikki syövästä, 2025b). Treatment aims to boost the body's immune system so that the body's natural defences are activated to target and destroy cancer cells. In past decade, significant research efforts have been directed towards harnessing the immune system to combat metastatic kidney cancer (Wallen et al., 2007) and the treatment is used for care at HUS when possible (HUS, 2025a)

Targeted drugs target cancer cells directly, resulting usually in fewer side effects (Kaikki syövästä, 2025e, 2025h). The use of targeted drugs requires a thorough study of the function of cancer cells to find suitable targets, which is usually done during the detection stage. Targeted drugs are often given as combination therapy and are already used in first-line treatment for some cancers. For example, using drugs blocking vascular growth, immune checkpoint inhibitors and treatments combining the two have been shown to extend life expectancy even in metastatic cases of kidney cancer (Mattila et al., 2022).

In recent years, significant advances in research have given rise to multiple novel, unconventional treatment methods. Debela et al. (2021) offer an overview of the most advanced and novel cancer therapies, including methods such as stem cell therapy. New therapeutic approaches have also been explored and evaluated for the treatment of renal cancer (Turajlic et al., 2018). At the HUS Clinical Trials Unit, some kidney cancer patients have early access to experimental treatments as part of ongoing research initiatives (HUS, 2025a). Mattila et al. (2022) refer to the relatively high cost of combination therapies to highlight the importance of targeting patients who are most likely to benefit from these treatments. However, further research is necessary to improve the identification of suitable patients, which will require the development of more effective biomarkers.

Adjuvant and palliative treatments are additional treatments to be given after first-line treatments. Adjuvant therapy, such as chemo- or radiotherapy, is received by patients whose main detectable cancer has already been removed to lower the risk of any type of renewal (Dong & Gewirtz, 2022). In kidney cancer, such prevention has not been proven to decrease the rate of tumour renewal. Palliative care (PC) is commonly known for relieving symptoms and addressing holistic needs in terminal stages (THL, 2024), but its integration into standard oncology practice is also recommended. It has been shown to improve physical well-being, patient satisfaction and alignment with care goals (Hugar et al., 2021) that all aid in recovery despite not being methods to cure the cancer itself.

3.3.4 Post-treatment survivorship

Taplin et al. (2012) highlight four stages for post-treatment survivorship in the cancer care continuum: testing, follow-up care, palliation and recurrence surveillance. In the HUS care pathway (HUS, 2025a), the frequency and duration of follow-ups for renal cancer patients depends on a physician's evaluation on the risk level of metastases. If the cancer is localised, the monitoring will last two to five years as most reoccurring cancers do so during this period. Chan et al. (2021) note that post-treatment survivorship care usually spans both acute and primary care environments, involving a range of professionals from medicine, nursing and other disciplines. As a result, the nature of care remains comparable to earlier stages within the complex cancer care continuum. However, they especially mention certain factors that challenge the delivery of high-quality, in-person survivorship care. These barriers come from, e.g. workforce shortages, limited access to interdisciplinary care, cultural differences and travel obstacles, particularly for rural or remote populations.

Over recent decades, telemedicine technologies have been progressively explored as a way to overcome challenges associated with survivorship care. The COVID-19 pandemic opened a new era for telemedicine (Yildiz & Oksuzoglu, 2020) and telemedicine is expected to remain as an integral part of cancer survivorship care. Implementing proactive follow-up systems and technology driven protocols is seen as one opportunity to reduce the risk of missing opportunities at critical final stages (Murphy et al., 2014). The World Health Organization, defines telehealth as

> "the delivery of health-care services, where distance is a critical factor, by all health-care professionals using information and communication technologies for the exchange of valid information for diagnosis, treatment, and prevention of disease and injuries, research and evaluation, and for the continuing education of health-care providers, all in the interests of advancing the health of individuals and their communities" (WHO, 2024, p. 2).

The use of digital solutions especially in post-treatment survivorship, for rehabilitation interventions, has been noted to improve the patient experience (Halvorsrud et al., 2019). Post-COVID-19 studies have also reported encouraging early outcomes, indicating that telemedicine can improve physical activity levels (Dorri et al., 2020), enhance accessibility to care in remote areas and reduce costs for both patients and healthcare providers (Arem et al., 2022). However, Arem et al. (2022) emphasise that telemedicine seems to be primarily working for the benefit of providers and therefore more extensive and generalised research from a patient perspective is still needed. Although Chan et al. (2021) acknowledged that telemedicine services can help manage certain psychosocial and physical challenges associated with cancer, there is a lack of supporting evidence for its effectiveness in other aspects of post-treatment survivorship care. Additionally, digitalisation can unintentionally widen the gap between individuals who are comfortable with technology and those who have limited access to or understanding of digital tools (Jewett et al., 2022).

3.3.5 End-of-life care

End-of-life (EOL) care focuses on maintaining a person's quality of life and supporting a peaceful and respectful dying process. As death approaches, care is tailored to reflect the individual's personal values, preferences and wishes. According to HUS (2025a), "good palliative care and psychosocial support are an integral part of cancer treatment". When the focus shifts from preventing to managing symptoms, PC at HUS aims to ensure a good and active life with the illness. PC should already be offered prior to this stage of cancer to aid with the stress and uncertainty caused by the illness. Early referral also increases the likelihood that patients receive the referral in time and are able to integrate palliative care into their lives even before EOL (Haltia et al., 2023).

However, the low availability of PC increases visits to the emergency department for EOL cancer patients (Earle et al., 2003; Henson et al., 2015). Offering PC earlier affects both the length of hospital stays and the need for aggressive EOL treatment (Cheung et al., 2015). When introduced to the patient's care early enough, PC decreases the need for acute hospital services in EOL, which in turn should lead to cost reductions (Haltia et al., 2023).

The evolving and multi-phase nature of kidney cancer care highlights the critical role of continuity and coordination: elements that can be better understood through patient journey modelling.

3.4 Patient journey modelling

In order to achieve the required transformation toward a new vision of patient-centred healthcare, health service systems require reimagining and redesigning to integrate technology and enable people to actively participate in co-creating their health (Patrício et al., 2020). The use of modelling languages in healthcare settings can help facilitate interdisciplinary collaboration and aid in meeting patients' needs and expectations (World Health Assembly, 2016).

Cassidy et al. (2022) define the recommended characteristics for the modelling of care pathways as patient-centric, integrated and EHR-supported. Integrating process modelling into patient care management can foster shared understanding among different actors, drive digital transformation and improve care outcomes (Ferrante et al., 2016). Moreover, it is essential to involve clinicians, who ultimately use hospital information systems and EHRs, to ensure these tools are both usable and capable of delivering the intended improvements in care quality (Kaipio et al., 2017).

Decision making is an inherent part of multidisciplinary care process definition (Combi et al., 2017; Pufahl et al., 2022). Burwitz et al. (2013) highlight evidence-based knowledge as essential for decision making during patient pathways. According to their work, any modelling language used for this purpose should support some level of evidence prioritisation to balance the evidence of test results with the recommendations of the system. For example, treatment decisions are made based on patient-specific criteria as the care pathway progresses and decision-support rules should be set up in advance to provide recommendations based on these criteria. However, if a medical professional decides to override the system's suggestion, their decision should take priority, as long as it is properly documented and justified. This emphasises that if the management of care pathways is supported by technologies, it must have even stronger support for methodologies to address all aspects of care.

Process modelling does not need to support full automation, as partial automation is more common in healthcare (Combi et al., 2017). However, for any type of automation, decomposing processes into smaller, reusable building blocks can be seen as a requirement. Combi et al. (2017) defined such elements as often having specific properties and responsibilities. For example, in the kidney transplant representation by Andellini et al. (2017), the automated process management system used sub-blocks which were divided into three key responsibilities: (1) generating a default patient pathway based on medical visit templates provided by an administrator, (2) scheduling and creating human tasks and visit templates within the planning period and (3) managing actions triggered by new patient events in the platform.

Process modelling methods aim to intuitively define patient pathway phases, and this is supported by graphical elements and a structured representation (Scheuerlein et al., 2012). Chronological and parallel process steps are ideal for describing medical workflows, while symbols make the models accessible and easier to understand, even for those unfamiliar with the modelling method. This in turn supports training and communicating with end users. The use of process models also supports the standardising of protocols and decision-making events which is helpful for reducing variability in care (Ferrante et al., 2016). Process models also support the technical requirements and serve as blueprints allowing the automation of activities and information flows. As such, they enable the identification of necessary software modules in care processes in a less ambiguous and more user-friendly manner (Kaipio et al., 2017).

In the context of healthcare transformation, service design is considered beneficial as it provides a user-focused, holistic, and iterative approach to creating new services (Blomkvist et al., 2010). Service blueprinting has been used for decades to represent the service delivery process from provider to customer (Bitner et al., 2008). Here, a customer's steps can be visually separated from back-end processes as a flowchart, but this choice does not sufficiently reflect the customer's viewpoint. In general, this approach is still a good starting point: focusing on customer experience as the core of service delivery management is more likely to achieve better customer satisfaction and organisational success. However, service blueprinting is argued to only support the delivery of processes planned by the service producer (Stickdorn & Schneider, 2011).

Customer journey mapping is usually part of the service design processes, but it is also utilised in managing implemented services (Følstad & Kvale, 2018). It is additionally seen as useful for shedding light on inconsistency between planned and actual processes (Halvorsrud, Kvale, et al., 2016). Patient journey mapping (PJM) is noted revealing these inconsistent gaps in care by understanding experiences and behaviour (Larsen et al., 2024; Soman et al., 2025; Vesinurm, Dunweber, et al., 2024).

Improving the kidney cancer care continuum requires improving all of its care stages. In order to do so, multiple aspects need to be considered. The World Health Assembly (2016) propose a framework to support the integration of people-centred health services. Strategies for integration should consider at least the five following aspects: (1) empower and involve people and communities; (2) strengthen governance and accountability mechanisms; (3) reshape the care delivery model; (4) improve coordination both within the health sector and across other sectors and (5) establish a supporting environment. Achieving progress in all five areas is considered crucial for building more effective healthcare systems, as shortcomings in any single domain may hinder overall advancement.

The implementation of clinical pathways has shown significant improvement in patient outcomes, in terms of both quality of life and morbidity (Aspland et al., 2019). Healthcare is a highly promising field for implementing process-oriented models but also a challenging one. While the advantages of organising and standardising patient care delivery have been widely acknowledged, the inherent complexity of patient pathways and the requirements of healthcare processes partially explain the pressing need for a standardised modelling approach (Ardito et al., 2020; Seys et al., 2019).

The standardisation of patient pathways begins with modelling languages that are used to represent and communicate them (Bogale, Vesinurm, et al., 2024). Within the service design approach, a variety of modelling notations have been proposed for patient pathways. Graphical models are one of the two dominant approaches for process-modelling (Lu & Sadiq, 2007). They represent activities visually as nodes, combined by control flows and data dependencies. General-purpose, visual approaches for patient journey modelling include the Unified Modelling Language (UML), the Business Process Modelling and Notation (BPMN) and the Customer Journey Modelling Language (CJML), each with their strengths and weaknesses. One easy comparison is to characterise them based on their points of focus: UML is software-centric, BPMN business-centric (Pahl et al., 2015) and CJML is human-centric, developed from the end-user's perspective (Halvorsrud et al., 2023). In the following sub-chapters, these three process modelling techniques are introduced and their prior use in patient care examined.

3.4.1 Unified Modelling Language (UML)

The Unified Modelling Language (UML) is a standardized modelling language by the Object Management Group (OMG) (2017). It is a unified language developed for object-oriented software applications (Hunt, 2003) and a notation that represents organised processes and systems as diagrams (Eriksson et al., 2000). UML includes a variety of diagram types that are categorized into two main groups representing either structural or behavioural information (Bhatt & Nandu, 2021). Structural diagrams show the system's fixed elements, such as classes, objects and interfaces, while behavioural diagrams focus on how the system functions, how data moves, how parts interact, and how the system responds to different stimuli over time.

UML responds to the requirements of patient process modelling especially by its different behavioural diagram subtypes:

- Sequence diagrams (SDs) are useful for visualising communication between patients and healthcare producers, with a simple and accessible notation (Object Management Group (OMG), 2017). However, they lack detail on process steps and do not capture key patient journey elements such as channels, phases, experiences or deviations (Halvorsrud et al., 2023).
- Activity diagrams (ADs) provide a more process-oriented view (Object Management Group (OMG), 2017). ADs support multiple actors in swimlanes and model activity workflows, data object flows, responsibilities and decision points (Halvorsrud et al., 2023). Still, they are typically institution-focused and not designed for representing individualised, patient-centred care pathways (Askari et al., 2013). Adapting ADs for this purpose often requires significant customisation.

Due to its generality, UML has been widely adopted for modelling clinical pathways in healthcare settings (Askari et al., 2013; Pahl et al., 2015). UML facilitates the analysis of process workflows, responsibilities and information flow across departments, making it a suitable tool for system-level healthcare modelling (Kumarapeli et al., 2007). For example, Shiki et al. (2008) use UML to model hospital-based cancer registration, demonstrating the utility of activity diagrams for visualising departmental workflows, use-case diagrams for defining roles and responsibilities, and class diagrams for structuring data relevant to cancer registries. Their results favour the use of a uniform language such as UML in cases where process modelling includes comparative analysis of processes from several institutions. Similarly, Askari et al. (2013) find ADs effective in capturing data and activity flows but recommend other notations for representing organisational aspects.

Overall, while UML shows potential for structured, comparative and modular modelling in healthcare, its applicability to patient-centred design remains underexplored.

3.4.2 Business Process Modelling and Notation (BPMN)

The Business Process Model and Notation (BPMN) is the leading standard for process modelling, standardized by Object Management Group (OMG) (2013). BPMN is a graphical notation that provides a standard for modelling business processes in a workflow format, much like UML activity diagrams. It includes a core set of symbols that are intentionally simple, allowing even those without extensive training to interpret them. At the same time, it includes advanced construction methods and various diagram types that enabling experts to represent more complex cases, such as exception handling and message-based communication (Combi et al., 2017).

The basic elements of a graphical BPMN process diagram consist of four basic objects: 1. Event, 2. Action, 3. Gateway and 4. Flow. Activities, events and additional sub-processes are connected by sequence flow and directed by gateways to indicate relations between them. BPMN is supported by various modelling tools and extensive professional and academic training opportunities are available.

Variability and uncertainty in the patient pathway structure complicates directly representing them as business process diagrams, but BPMN has still been applied in several healthcare contexts, either as is or in combination with other notations. Barbagallo et al. (2015) use BPMN to represent a sequence of surgical conditions for optimisation of the process of an operation room (OR). This approach resulted in the scheduling of approximately 30% more patients compared to current practices. Combi et al. (2017) emphasise the use of business process models in healthcare workflows to identify shortcomings and procedural bottlenecks. Zerbato et al. (2015) model the process of catheter-related bloodstream infections with BPMN and used UML for the data modelling, arguing that using only BPMN to model a decision-intensive care pathway represents a misuse of its intended purpose. The following decisions made in their study are taken into account when considering the modelling language for the kidney cancer pathway:

- Using "*call-activities* to modularize the process and decompose complex, diagrams into smaller building blocks" (Zerbato et al., 2015, p. 350) for reoccurring activities, e.g., blood tests.
- Using graphical elements *data object* and *data store* to underline the high dependency of data flows. For the objectives of their study "it is not in our interest to specify internal variables for tasks and gateways, as required by executable BPMN" (Zerbato et al., 2015, p. 353).

Combi et al. (2017) advocated the use of BPMN when specifying different roles in healthcare organisation is relevant, as separating activities performed by different roles is straightforward through pools and swimlanes. BPMN diagrams were considered appropriate for illustrating the process control flow with an adequate level of detail and expressiveness, accommodating varying degrees of structural complexity and automation support.

The acknowledged limitations of BPMN include its ability to represent temporal relationships, incorporate domain knowledge and integrate complex structural data (Combi et al., 2017). Although BPMN shows slightly better results in complexity-related criteria, both BPMN and UML perform similarly in practice, and their suitability largely depends on the specific use case (Recker et al., 2009). Capturing the patient-centred aspect could limit BPMN's applicability for modelling patient pathways as it's not one of its intended use cases. However, BPMN allows the integration with other OMG standards, such as the Decision Model and Notation (DMN) (Object Management Group (OMG), 2024). DMN has been applied as a complement to BPMN, helping overcome its shortcomings by effectively modelling the decision-making processes and informational aspects commonly found in healthcare environments (Pufahl et al., 2022).

BPMN still falls short in its ability to represent human behaviour and the contextual conditions that influence such behaviour (Tehrani et al., 2013). Combi et al. (2017) also discuss that overcoming the shortcomings of their research required the exploration of additional modelling extensions. The integration of such approaches was seen to demanding higher expertise, which doesn't suit the idea of less ambiguous, user-friendly patient care process models (Kaipio et al., 2017).

Additionally, implementing BPMN as a modelling approach often requires significant investments of both time and human resources (Scheuerlein et al., 2012). Burwitz et al. (2013) evaluate BPMN to model clinical pathways, finding that it does not meet requirements to perform variable and parallel flows, or support evidence-based decisions. Its lack of these features challenges its use as a part of daily clinical routines.

3.4.3 Customer Journey Modelling Language (CJML)

Customer Journey Modelling Language (CJML) is a structured, visual language that focuses on representing the customer's journey and experience throughout their interactions and touchpoints with a service or product. It is intended for a broad audience to be used without prior experience in modelling languages. CJML places focus on the customer's perspective (Halvorsrud et al., 2014). In the context of healthcare, this allows CJML to be used to model patient journeys by especially emphasising the patient's role and experiences throughout the trajectory.

CJML is a relatively new visual language compared to UML or BPMN and is actively being developed. The key building elements of CJML are listed by Halvorsrud et al. (2023) as journeys in either a journey or network diagram, with touchpoints as action and communication points, planned and actual journeys, and many more. In the central of these elements, it places actors: at least one service provider, delivering the services, and one end-user using those services, e.g. customers or patients. CJML aims to bring clarity to how the service provider communicates or interacts with customers. A touchpoint is where these elements collaborate: it does not only hold information about the interaction but also, for instance, includes information of who initiated the interaction, the channel used for this and whether the outcome is completed, missing or failing.

CJML has two diagram types: journey and network diagrams. Examples of the main building blocks are visualised in Figure 3. Both diagram types allow representing planned and actual journeys, but the simple journey diagram emphasises the deviations in a clearer way. The network diagram, presented as swimlanes, is the service delivery network approach. It's a practical concept in services requiring a network of actors, like complex patient journeys. In the swimlane approach, each actor is assigned their own lane to clearly differentiate the network's message flow. Each communication touchpoint is duplicated to highlight the initiator using coloured (typically blue) boxes and arrows are used to indicate the direction of knowledge, revealing both the sender and receiver of each communication point.

It is important to note that CJML is not exclusively patient-centred; it emphasises placing individuals at the centre of the process, whether they serve as patients, providers or other producers. Its use in the patient journey can require flexibility to meet the requirements and specific qualities of complex healthcare processes. However, this perspective also helps to consider interactions between HCPs, which play a significant role in a patient's journey.

Larsen et al. (2024) explore the use of CJML for the case of kidney cancer, including both patients and HCPs, and their findings support modelling with CJML to include both the journey and network perspectives. They demonstrate that the language allows the illustration of a broad level of detail, depending on the context. Bogale, Solem, et al. (2024) visually model the common MS patient pathway with CJML and while their approach aims to comprehend organisational care processes, further considering the individualistic needs is recommended. Overall, CJML has been noted as a user-friendly approach even for complex journeys (Halvorsrud, Haugstveit, et al., 2016).

A distinguishing factor of CJML is its support for customer experience. In the network diagram, customer experience is expressed in a separate swimlane (see Figure 3 below) and as call-outs from a communication point in the patient journey diagram. The patient's experience is visualised with emoticon based rating and self-reported input in text format. This feature is not used in this study when modelling customer journeys, but integration is noted as useful if evaluating customer experience collected from interviews, questionnaires, etc.

Another differentiating feature is an extension including notation for uncertainty: in occurrence, communication channel or other undefined character (Halvorsrud et al., 2023). This is well aligned with the nature of complex patient journeys and could help visualise points requiring improvements or PJDs. Lastly, Halvorsrud et al. (2023) discuss CJML's different design perspective in relation to UML and BPMN, which is inherently human end-user-centred. This has inevitably affected the visual choices and simplicity of the options but has also, for instance, challenged the delimitation of the target group and leads to fragmented knowledge even around key elements. They also highlight that CJML has several limitations that are under development.

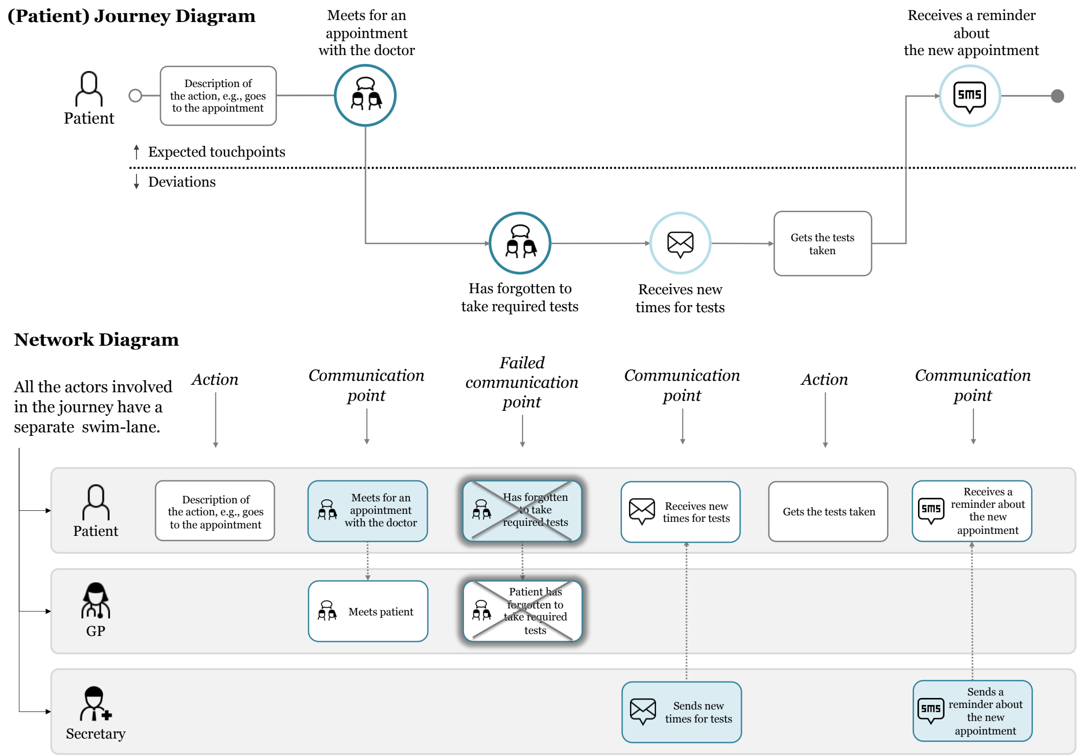


Figure 3 CJML Diagram elements

3.4.4 Standardised modelling tools

The advantages of using standardised tools were evaluated to be diverse. Primarily, their process and decision modelling rely on graphical and easily comprehensible notations. These features can be complemented further by other standardised approaches in order to fit the requirements of the patient pathway and healthcare domain (as in Combi et al., 2017; Zerbato et al., 2015). Second, several tools support their integration and could already be in use in some parts of healthcare organisations. UML and BPMN are standardised by OMG, while CJML is yet to be standardised.

For the models of this study, following building tools were assessed:

- UML: Pahl et al. (2015) explore web-based UML tools for clinical pathways, identifying viable options varying in detail, ease of use and learning curve. However, accessing the tools suggested in their review was not successful for the purposes of this study. UML can be modelled in miro.com with a limited availability on all its elements.
- BPMN: a well-functioning, free web-based demo version was found on bpmn.io. The demo has pre-build objects and tools for creating the process model. Especially aligning objects together easily and creating the

flow between them is beneficial. Although the demo version does not include all possible versions of objects, the available object alternations are seen as adequate for the kidney cancer model of this study.

- CJML: All available visual notations (diagram types and symbols) and terminology (definitions and attributes) can be found from cjml.no. CJML also has a beta-version available at https://cjmlui.netlify.app.

3.5 Summary of the literature review

The challenges of healthcare have been acknowledged for a long time and process modelling itself is not a new concept for simplifying its complexities. Therefore, for defining the approaches and the nature of the problem, literature was relatively conclusive. However, findings were scattered throughout a wide time frame. To have the most recent view on the required definitions, more recent research was explored, for instance, Bogale, Vesinurm, et al. (2024) and Vesinurm, Sylgren, et al. (2024).

The literature identifies healthcare as a uniquely complex service domain, where both patient characteristics (e.g., chronic conditions and psychosocial needs) and systemic fragmentation contribute to non-linear, unpredictable care pathways. Key contributing factors include open system dynamics, information asymmetry, co-creation requirements, and the tension between public service obligations and resource constraints (Vesinurm, 2025). Despite existing CGs and pathway structures in the EHR system, current modelling approaches often fail to capture the dynamic, patient-centric and interdependent nature of care.

Haywood et al. (2006) highlight that despite the emphasis on patient-centred care, many patients with multiple chronic conditions still experience a gap between expectations and the actual care delivered. Many reviewed studies were qualitative case studies from single hospital contexts. There is a noticeable lack of literature where patient-centred models are implemented in practice, evaluated through quantitative methods, or tested using real-world data such as clinical registries. A few studies (e.g., Cassidy et al., 2022; Combi et al., 2017) move closer to this goal and were therefore especially relevant for this study. This gap between the conceptual emphasis on patient-centredness and its limited practical and measurable implementation is significant. It highlights the need to move beyond structural improvements and to ensure that care delivery also captures patients' actual experiences and subjective perspectives.

Given the fragmented nature of care and the variability of actual care delivery, the patient journey approach emerged as the most suitable for this study. In this context, when addressing patient journeys, elements of both *journeys* and *pathways* are used interchangeably. In accordance with the definitions, *pathways* are used to indicate planned care and *journeys* reflecting the actual, often nonlinear care experience. In the empirical part of the study, solely the term patient *journey* is used for simplicity. While this distinction is not always consistent in literature, the underlying focus on patient-centred and co-created care is maintained throughout the following sections.

Specific to kidney cancer, the literature highlights several typical features that increase care complexity: repeated diagnostic and follow-up testing, multiple care phases involving various HCPs, and a strong reliance on effective communication between patients and care providers and producers. These elements further support the need for agile, flexible modelling approaches that can accommodate change, uncertainty and collaboration across disciplines.

Finally, the modelling language definitions and their assumptions about process linearity and structure inevitably influence their applicability to patient-centred modelling. The literature review points to differences and limitations in how UML, BPMN and CJML represent changing patient journeys and some aspects of patient-centrality. In the following chapters, the modelling approaches are comparatively evaluated to see which best meets current needs.

4 Analysis

In section 4, results from workshops and creation of the artefact are presented. The problem is identified in part 4.1. Comparative analysis of modelling methods is presented in 4.2, leading to further introduction of the chosen method in 4.3. In part 4.4 patient journey models are presented for phases of care continuums and other alternative cases uncovered in expert workshops. Part 4.5 shares improvement proposals for the modelling and 4.6 presents the demonstration and evaluation feedback. Final development proposals are listed in part 4.7.

4.1 Identifying the problem and motivation

During this study, three workshops were held in collaboration with experts, one kidney cancer specialist (KCS) and two nurses. Additionally, one interview was held with a kidney cancer patient, of which the latter mainly validated information provided by the three healthcare professionals (HCPs).

Expert workshops underlined the typical elements that are present in most kidney cancer cases from the HUS Cancer Centre's perspective. Four phases of care segments are highlighted: detection, diagnosis, treatment and post-treatment survivorship. These findings align closely with the types of care segments described by Taplin et al. (2012). Each phase was examined in the literature review, but in-person workshops provided more in-depth information of the individual steps, stakeholders, requirements of care and communication flows involved in and between each phase. On top of this, additional systems affect the care process. For instance, electronic health record (EHR) systems creating a parallel network of producers by handling patient records, booking appointments and sending notifications. All cancer cases are unique, but discussions with experts provided sufficient understanding to draw a typical, planned patient pathway, while simultaneously discovering optional, actual patient journeys and the most common disruptions events.

Transitions in care were a focal point of this study's empirical research, bridging the relationship of interfaces (Anhang Price et al., 2010) and shortcomings (Zapka et al., 2003) by focusing on knowledge sharing and communication between patient and care providers. Therefore, workshops aimed to discover how communication flows in separate phases. A patient's deteriorating condition is used as an example of such a phase. When a patient contacts a care team for additional support for new symptoms or deteriorated condition, it's either via phone call or through messaging services. Both require evaluation of possible next steps, e.g., in case of emergency, or forwarding the status to nurses, and possibly also to KCSs, relevant to the patient. Most of these communication steps are not present to the patient who waits for instructions on their condition.

Through the workshops, it is also observed that transitions contribute to the varying interactions and influence of different roles across the patient journey. At the start of a care process, the link between primary care and the patient is a key factor in how detection progresses to diagnosis. As patients progress to the treatment phase, the team of KCSs becomes their primary influence. However, this influence might diminish once a patient completes their oncology treatment and transitions into long-term survivorship. Furthermore, various forms of care consist of separate phases within the overall process and include interactions between patients and other HCPs across multiple organisations.

Expert workshops couldn't expand to experiences of using or following care pathways from the patient's perspective, and thus the knowledge generated of the topic relies on literature and the single patient interview. According to KCS, patients are aware of how their care plan is progressing. When asking whether they see sharing the care plan with patients as an important practise, they wish not to give patients access to all details. Sharing is believed to raise questions and ambiguities. Experts did not directly embrace the idea that making care pathways visible to patients would improve the flow of care and avoid unnecessary steps. However, the patient interview raised the topic from the opposite perspective: heavy treatment periods and waiting times affect the mind and can lead to forgetting relevant information, but the treatment cannot be reviewed retrospectively as there is no corresponding patient journey available. Not having their patient journey available goes against the findings of the literature review and is believed to highlight the underlying problem: current patient care plans are not designed to support patient involvement in managing their own care.

Kidney cancer patients are cared for by several different care providers. The beginning of a care process is a great example to highlight the multi-producer nature of care, leading to initial communication disruptions if a patient's data is also distributed between multiple different healthcare producers. If a patient's information comes from different recording systems, due e.g., having previously lived in another county, the process for requesting access requires permission from the patient. Patients can allow sharing their previous patient information which fastens the diagnosis process, but if they refuse, the process may take significantly longer. Experts discussed that it could be due to insufficient information on why such data is required in the first place. Therefore, if the patient is aware of the required data process behind their treatment, they could allow the use of information both in the beginning but also in the next phases, e.g., extending authorisations to family members who can be involved and informed about the stages of care.

The patient interview offered an important notion of the communication disruption from the perspective of post-treatment survivorship. According to their experience, the KCS in charge of treatment and nurses can have varying opinions of surveillance. The KCS may prescribe procedures to be carried out at home, while nurses prefer these to be carried out together in an appointment setting. Inconsistencies in the way different nurses communicated information with the patient also lead to confusion on the patient's side.

On a conceptual level, dividing care between multiple providers is believed to drive the prevention of medical errors. However, the number of providers is underlined as causing communication disruptions and the initial challenges of accessing information. The impact of organisational changes has been studied, finding that it decreases the success of the care stage (Anhang Price et al., 2010). According to the workshops, recent changes have affected care at HUS and will assumingly continue to do so as long as the search for a nationwide patient information system is in progress. This discovery aligns with the literature findings and constitutes the second problem point of the study: dispersed information sharing and separate electronic health record (EHR) systems challenge the quality of patient care.

When discussing factors decreasing the quality and effectiveness of patient care, four areas were identified:

- **Patient journey disruptions (PJDs)** emerged in previously mentioned challenges in sharing and accessing a patient's medical data or varying treatment instructions from different care providers. Additionally, the patient interview underlined the occurrence of misleading information in received letters or in the notes recorded in the system, which is also seen as a PJD (Vesinurm, Sylgren, et al., 2024).
- **Uncertainties in the care process** were apparent, for instance, when a patient's condition worsens. Patients have options for contacting their care team, but processes triggered by this contact are not planned and vary greatly. This in turn may lead to a patient's case being bounced between different producers using different communication channels.
- **A patient missing an appointment** leads to a rather standard procedure. Discussions mentioned that each missed appointment, or other disruption, should always be reported and recorded to an EHR. In cases where the patient has a tendency to forget labs, the care team might have their own alerts to check on the patient and remind them beforehand, despite the system alerts sent to the patient.

- **External bureaucracy** affects care especially when applying for reimbursements for medicine expenses from Kela. The process for obtaining a new Kela reimbursement statement was seen as highly inconvenient and old-fashioned, and the process can take a long time.

The multi-producer environment involved in kidney cancer care was evident in workshop findings. The process picture created in workshops included a minimum of 10 separate care producers, emphasising that the reality of this network is inevitably much larger. In contrary to the previously highlighted problems, some of the workshop findings were not mentioned in literature. For example, no record of monthly holistic care meetings were found. While this may differ between treatment practices in different countries, it highlights that organisational factors influence aspects of care e.g. long waiting times. Each new care plan is approved by multiple HCPs, which automatically increases the waiting time between treatments. When everyday life revolves around treatments and their outcomes, waiting can easily create frustration. Frustration does not remove the importance of careful diagnosis and treatment planning but rather emphasises the potential of the patient journey approach to create space for the patient during intense periods of care.

In general, cooperation between HCPs was seen as highly useful. Alongside treatment planning, it allows HUS to try out new treatments. As medical research continues to evolve and new medicines appear on the market, not every specialist is aware of them. Due to collaboration with others, patients can be offered opportunities to participate in new trials if none of the previous rounds of treatment have worked. This further highlights the importance of effective information and knowledge transfer, making it a necessary quality of the created artefact.

4.2 Defining the objectives of the patient journey model

4.2.1 High level objectives of the model

The objectives guiding the development of the model are outlined as follows:

- Accurately describe the patient journey in the kidney cancer care process.
- Support the efficiency of kidney cancer care processes.
- Improve quality of care.
- Explore opportunities for integrating EHR data.
- Contribute to the ongoing search for a common modelling technique.

The following section delves deeper into the defined objectives.

The first of the high-level objectives is to create a model that succeeds in expressing the nature of the kidney cancer care process as a whole. Given the complexity of patient journeys, characterised by multiple stakeholders, decision points and individual care, the model should effectively reflect the nuances of patient-provider engagement and the coordination of healthcare services.

Supporting efficiency and improving the quality of kidney cancer care can be seen from many points of view. Improving quality of care also relates to the improvement of patient experience alongside the actual care pathway. Factors reducing PJDs , like incomplete information and uncertainty in the care itself or the goal of care, are also seen as benefiting the quality of care and co-creation of health (Vesinurm, Sylgren, et al., 2024). As one of the objectives is to enhance cost efficiency without compromising the quality of care, the proposed solution must contribute to streamlining the process, not necessarily by increasing it but by offering methods for maintaining and acknowledging phases of improvement. Improving quality of care is rooted in existing care debt, which makes ensuring better care a national objective.

The two main problem areas, the four factors diminishing the quality of care, along with the emphasised qualities, underline the third and fourth objectives. The chosen approach should consider the entire care journey, rather than focusing solely on the planned care process, and align with technical requirements, such as integration of EHR data. This builds towards the fifth, greater objective for a common patient-centred modelling approach to which the model should participate and allow the exploration of potential developments in the modelling technique.

4.2.2 Requirements for the modelling

Based on literature findings and the objectives and problems identified in 4.1, requirements for the models are as follows:

- **A patient-central, co-creative approach** that supports patients themselves to oversee their care.
- **Clear information and knowledge transfer** to prevent discontinuity, gaps and uncertainties in the care process, and support for better communication.
- **Flexible modelling capabilities** to represent the multi-producer environment and deviations from planned care, along with fulfilling the needs of accurately describing complex decision-making events.
- **Acknowledging data integration** as it is mandatory when standardising operational routines and leveraging EHR systems.

To present patient processes in a complex multi-producer environment, each modelling method is evaluated according to the following requirements, in explicit order of priority:

1) R1: Patient-centrality
2) R2: Clear information and knowledge transfer
3) R3: Flexible modelling capabilities
4) R4: Acknowledging data integration

This prioritisation is based on previous studies and literature, workshops and what needs to happen in the bigger picture. Literature revealed the need for patient-central approaches and workshops underlined the importance of well-functioning communication and information sharing practices.

As multiple decision criteria were to be considered for evaluation, a weighted prioritisation matrix is applied to provide clarity. Four requirement criteria were ranked in descending order of importance. The first criteria *Patient-centrality* carries the highest weight in the assessment, followed by the second, third and fourth with decreasing significance. The weighting is applied by assigning the highest-priority category a fourfold influence relative to the others. This ensures that the most critical factors exert the greatest impact on the overall evaluation while still accounting for all relevant aspects in a structured and transparent manner.

4.2.3 Evaluation of the modelling techniques

Evaluation of the models for the solution was simple. Each requirement criteria was assessed on a scale 0-2, as presented in Table 5:
- **0** indicates that the method does not support the requirement criteria
- **1** indicates partial support, but some elements are missing
- **2** indicates sufficient level of support

After grading each model's performance on each of the four requirements, these assessments were multiplied based on their weighted priority, leading to a weighted prioritisation matrix (see Table 6):
- R1: Patient-centrality, **weighted by 4**
- R2: Clear information and knowledge transfer, **weighted by 3**
- R3: Flexible modelling capabilities, **weighted by 2**
- R4: Acknowledging or supporting data integration, **weighted by 1**

Table 5 Evaluation and grading of requirements

	Patient-centrality	**Clear information and knowledge transfer**	**Flexible modelling capabilities**	**Supporting data integration**
Weight:	**4**	**3**	**2**	**1**
UML	0: No record.	1: Partly supported, indicating initiator and transfer in the underlying system structure but no channel.	1: Partly flexible but lacking capability to present complex nuances. Can be integrated to other notations capable of such levels of detail.	2: Data integration supported.
BPMN	1: Partly supported, mainly planned pathways.	2: Supported, indicating both the initiator, receiver, and transfer channel.	2: Supported, possible to integrate notations that offer missing capabilities. Standardised, which could limit some levels of detail.	2: Data integration supported.
CJML	2: Supported, both planned and actual pathways.	2: Supported, indicating both the initiator, receiver, and transfer channel.	2: Supported, especially agile for indicating both planned and actual pathways. Adjustment and development capabilities are high as language is still partly under development.	1: Acknowledged, support not yet in the development scope.

Table 6 Weighted prioritisation matrix of evaluated models

Weight	R1 **4**	R2 **3**	R3 **2**	R4 **1**	**Wtotal**
UML	0	3	2	2	**7**
BPMN	4	6	4	2	**16**
CJML	8	6	4	1	**19**

Based on the weighted requirements, CJML is chosen as the modelling language for the kidney cancer patient journey, with a score of 19 compared to BPMN's 16. UML's lack of patient-centric support was critical to its unsuitability, despite partial applicability in other criteria. Both well-performing approaches, BPMN and CJML, were deemed as applicable for the defined purpose. However, in the light of the current direction in healthcare, prioritising a patient-centric approach for actual journeys was considered highly relevant.

4.3 Design and development of the patient journey model

Based on the defined objectives, the research artefact was created using CJML. Next, a summary of the care phases is given along with examples from the artefact. The modelling is primarily based on knowledge from the workshops, which has been supplemented by findings from the literature, ultimately specifying the stages of a kidney cancer care continuum.

4.3.1 Defining the applied visual CJML notations

CJML models were created in Microsoft PowerPoint, following the official visual notations of diagrams. To present patient care process in a complex multi-producer environment, following concepts of CJML were used, with illustrative examples provided in Figure 4.

CJML has two diagram types: **journey and network diagrams**. Elements of both the journey and network diagram are used to test whether they would work or not. E.g., decision points are introduced as tools of journey diagram, but they are heavily needed in modelling the kidney cancer care process with the network diagram. An example of distinguishing the diagram types can be found from the literature review, in Figure 3 (p. 55).

Journey types in CJML are either **planned** or **actual journeys**. As data from workshops includes information on both the planned process and potential actual events, this CJML modelling requires combining elements.

The types of touchpoints depend on whether communication is included or not. If the communication point has a sender (initiator), then a receiver that is presented in their corresponding swimlane. The sender is visually represented with a darker layout than the receiver, with the points being otherwise similar rounded squares containing the relevant symbol and text. Activities that do not require communication are more simply marked with rounded squares, solely containing text.

Connecting objects in CJML are of two types: **sequence flow** or **message flow** objects**.** Sequence flows, represented with solid line arrows, are used in decision-making situations and are optional in network diagrams. Message flows, represented with dotted line arrows, are required to be used with every communication point and indicate the direction of messages from sender to receiver.

Symbols are used for two purposes in this model: 1. to represent actors and 2. to represent communication channels. CJML has a dedicated set of symbols for use in a healthcare context, and these were the only symbols used in this model.

Decision points represent moments where paths can diverge into multiple potential directions in both planned and actual journeys. This is depicted with a small diamond shape, dividing the sequence flow arrow into two. The decision point is not officially part of the network diagram, only the journey diagram, but this study will still use it in practice. The decision point is slightly modified from the journey diagram element and used when there are two or more path alternatives (e.g., the patient chooses between two types of medication, or the doctor decides the form of upcoming contact). Further justification for the choice is provided in section 4.5 which suggests proposals for improvements.

Time is expressed with a **time axis** in the diagram running from left to right. The passage of time and **waiting time** are visually represented with a white object with purple stripes. The size of the waiting time object is indicative of how much time it takes. The amount of time can also be indicated with an additional note. As time in CJML is running left to right and no sequence flow arrows were used to indicate order of activities, the importance of correctly aligning activities vertically increases.

All of the above-mentioned diagram elements are placed within **swimlanes** in the network diagram. All actors participating and relevant to be included in the journey have a separate swimlane. To further structure the diagram, it can be divided into **phases** which are indicated by a separate, purple lane above the swimlanes.

Compliance is illustrated through **deviations** from the planned journey, where the boundary shape conveys the status of each touchpoint. For instance, a line crossing through a touchpoint indicates a communication failure (see Figure 3 in literature review).

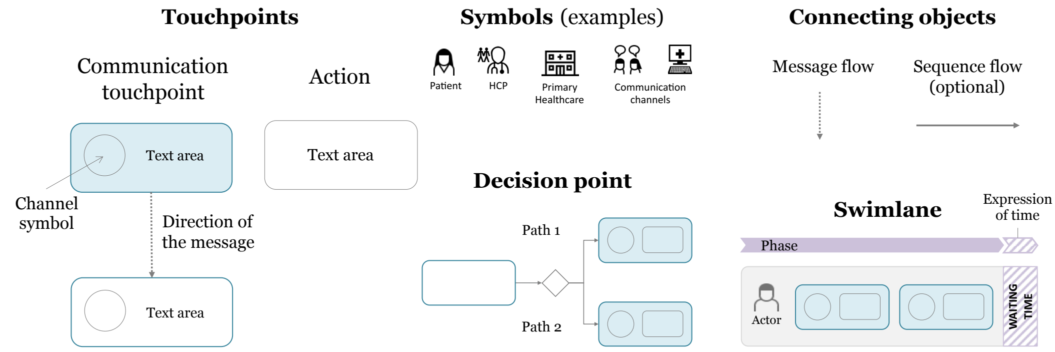


Figure 4 Used flow objects, network diagram

4.4 Modelling the kidney cancer patient journey

In this section, a summary of each care stage is provided and illustrative examples of parts of the patient journey models are presented accordingly. Full models, of which the examples are snapshots, and special cases can be found in Appendix C.

Insights from the workshops aligned well with findings from the literature review, and therefore models are sectioned according to the care continuum stage: detection, diagnosis, treatment, post-treatment survivorship and end-of-life care. Decisions made in modelling are based on literature review and the understanding for the build required familiarising with the guidelines and examples of earlier work. As models are built based on understanding from workshops, the level of detail varies in relation to the relevant workshop insights and the capabilities of CJML.

Previous studies have shown that CJML is suitable for representing both planned and actual journeys (Larsen et al., 2024). Taking both individual and multi-provider journeys into consideration when modelling is recommended, although this can be a challenge (Bogale, Solem, et al., 2024).

Therefore, the models made in this study aim to be comprehensive, using a modelling approach that captures individual nuances and high levels of detail while also handling simpler cases elegantly. To maintain clarity and readability, very rare or exceptional care cases were excluded.

The modelling process began once the modelling elements were selected. Each care stage was modelled individually. Participating actors were represented on separate swimlanes, and care phases were marked with phase indicators at the top of each diagram. Identified touchpoints were then added along these swimlanes, and message flows were added to show the direction of information exchange. Clear labelling of each touchpoint was essential to indicate what information is shared or what action is taken.

The created diagrams aim to include all relevant elements, namely the actors involved in care (e.g., patients, HCPs, support organisations) and any dependencies or interactions between touchpoints. The EHR system is placed on a dedicated swimlane to illustrate data flow. These goals are addressed as thoroughly as possible using the available qualitative data.

4.4.1 Detection

As kidney cancer patients usually note rather minor changes in their health, the detection part includes the exclusion of alternative diagnoses. Patients usually seek care from primary healthcare where a general practitioner (GP) performs the initial evaluation and chooses the next steps for examination. A referral to the HUS Central Hospital is usually needed for booking and invitation for imagining. The referral level depends on the stage of urgency (most urgent 1-7 days, in-between 8-30 days, and non-urgent referral >30 days). Workshops clarify that the detection phase ends when the patient is transferred to special health care.

A referral can also come from a private cancer hospital (e.g. Docrates) or through a contact with the patient's occupational health doctor as shown in Figure 5. If initially treated in private cancer hospitals, patients are transferred directly to special care and thus never visit primary healthcare. Occupational health usually performs the same procedures as a GP and sends referrals directly to imaging and to the urologist in special care. However, some patients can suffer from particularly severe symptoms and seek help from the emergency room, where they can be transferred directly to the ward. This deviation is not shown in the modelling as it is one of the special cases of kidney cancer.

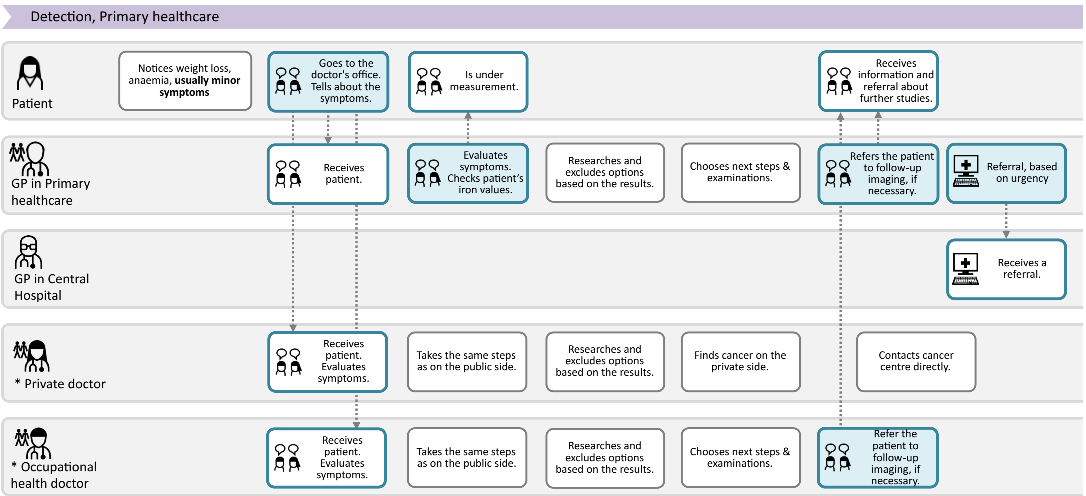


Figure 5 CJML model of the beginning of kidney cancer care

4.4.2 Diagnosis

Phase 2 of renal cancer care at HUS, *getting a diagnosis*, begins with a patient referred from primary healthcare arriving at HUS. Before inviting a patient to the outpatient clinic, a GP reviews the case, plans the additional examinations and gives a treatment recommendation. Diagnosis leads to either proving that nothing is wrong or further evaluating the cause of the abnormality.

The final confirmation of diagnosis comes from imaging results. The first diagnosis is performed by a urologist that evaluates the stage of cancer, 1-4, and whether it is spreading or not. The urologist oversees non-spread stages of 1-2/3 where surgery is the primary line of treatment. Responsibility is transferred to cancer care only in stages 3-4, i.e., when the cancer has spread. This division in the modelling is represented as dividing the swimlane to two inclusive lanes, for both the patient and care provider (see Figure 6).

A proper diagnosis of stages 3-4 cancer is given in monthly, common regional cancer meeting that evaluates each cancer patient and defines the type of treatment. The patient is given the opportunity to hear the results in a call before the meeting. However, it is recommended to go through the results together face-to-face to support the emotional response.

Before the initial meeting, the patient's case is presented to their own KCS that will be looking over the treatment process. This specialist, accountable for the patient, goes through the patient details with the cancer nurse before the first meeting with the patient. These interactions leading to the first meeting are represented as a CJML model in Figure 7.

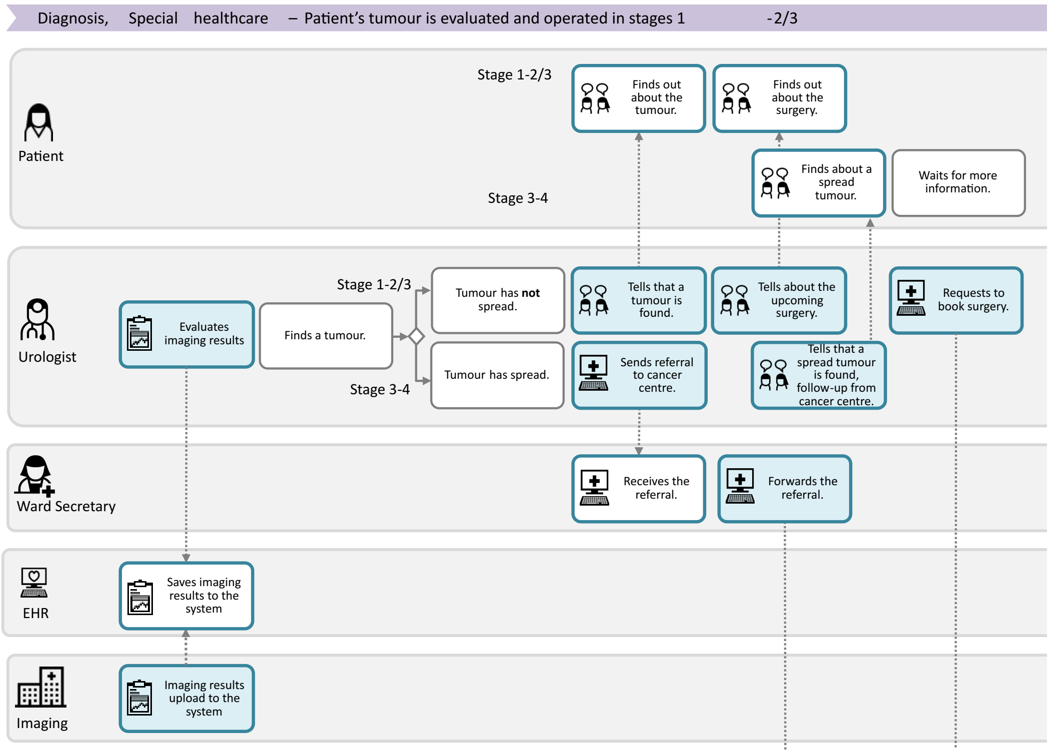


Figure 6 CJML model of diagnosis: the division of diagnosis process into two different lanes

In the first meeting with a patient's own KCS, the patient hears about their diagnosis, what will take place next and is informed about required tests and information before starting treatment. Then, the patient meets directly with a cancer nurse. The aim of this meeting is to support the patient after hearing about the diagnosis and discuss preferences for treatment. For example, if a patient is afraid of needles, infusion is not the best method. The nurse is also responsible for organising the next meeting and informing the patient about it. The patient should also receive information on where and how to find support. Workshops highlighted that sometimes this help is offered at once after the first meetings if support is available at the cancer centre during the same day.

4.4.2.1 Patient perspective

An alternative example was revealed in the patient interview, where their tumour was confirmed as cancerous not in a separate meeting but in a routine-like conversation on the ward. Their kidney cancer was treated in the urology centre solely as a tumour that had to be operated. It was revealed to be cancerous only after the surgery.

Responsibility of care was transferred to the cancer centre only after the cancer had renewed a couple of times and spread to the lymph nodes. The patient was given a choice to decide whether they preferred to stay at the urology centre or transfer to the cancer centre. However, the patient did not feel they understood the difference between these options. Once the patient's care was transferred to the cancer centre, they were given their own KCS responsible for their care. This was seen as a positive thing. Only then the patient also received information about available support channels.

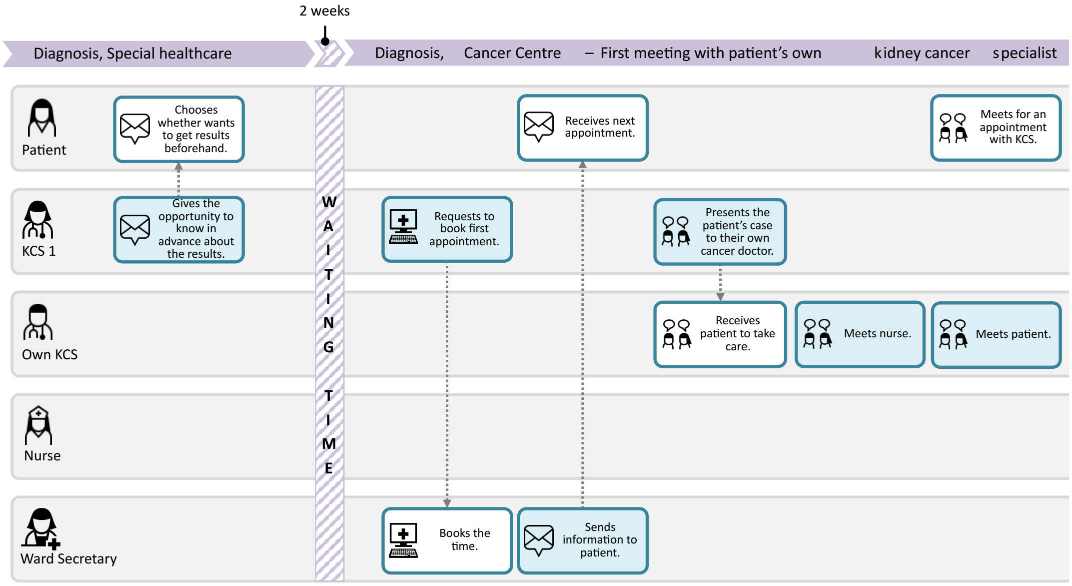


Figure 7 CJML model of diagnosis: touchpoints prior to a patient's first meeting with a kidney cancer specialist

4.4.3 Treatment

For the start of treatment, patients have taken certain examinations that confirm the possibilities of care (e.g., mandatory head scan) and fill in forms of, for example, past and current diseases and used medication. Patients receive a time for an initial treatment appointment either by phone call or a letter, depending on the urgency of treatment. Each start of treatment is first gone through together in person with a nurse, as shown in Figure 8. Depending on the type of medication, patients either start their treatment by getting the appropriate medication from a pharmacy or by meeting with their infusion nurse for the IV.

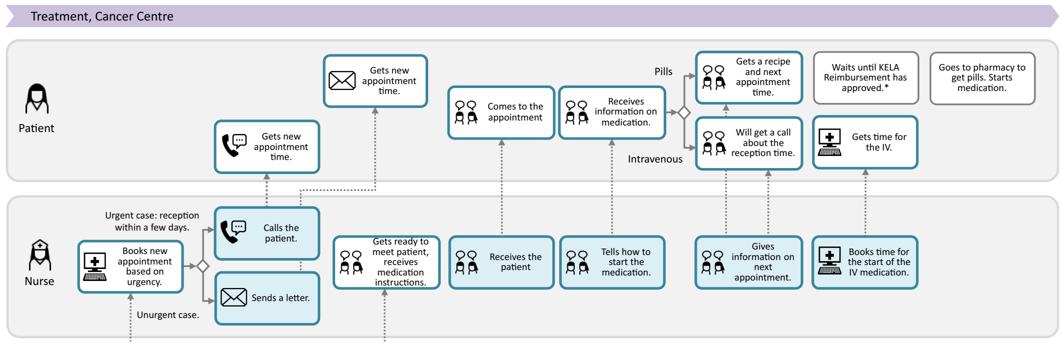


Figure 8 CJML model of treatment: starting medication

4.4.4 Post-treatment survivorship

Surveillance of treatment depends strongly on whether medication to stop progression of the disease can be found or not. When an effective medication is found and the patient's condition remains stable, the surveillance process is relatively straightforward. It involves regular blood tests and control appointments every 2-3 months for the rest of their life.

However, diseases showing signs of progression trigger a sequence of communication touchpoints, as represented in Figure 9. Then, a more active surveillance approach is necessary, entailing the exploration of different lines of treatment if alternative options are available. During this active surveillance phase, each medication is evaluated for its effects over a one-month period, during which noticeable results should appear.

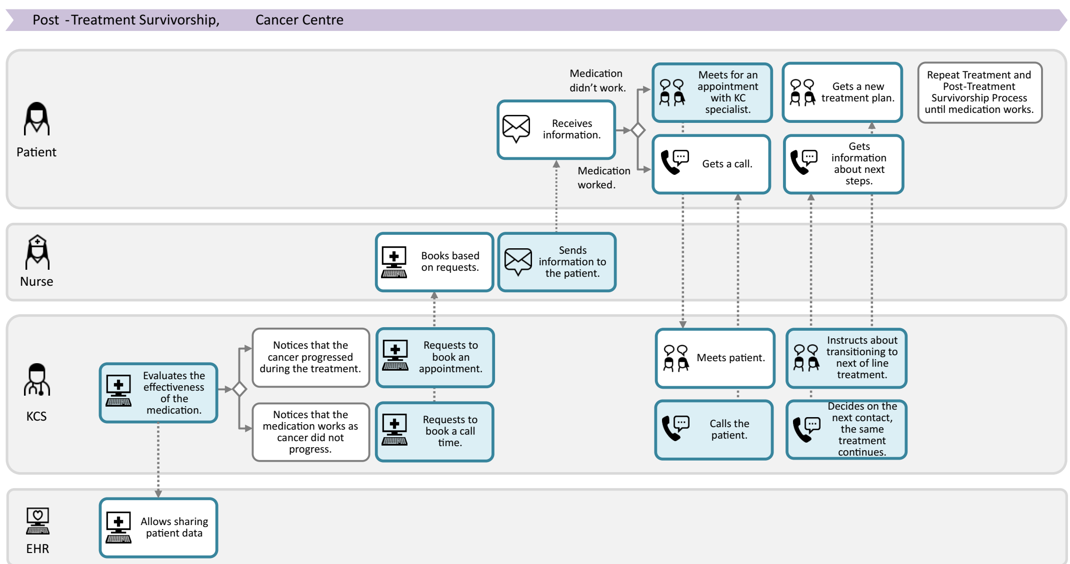


Figure 9 CJML model of post-treatment survivorship

4.4.5 End-of-life care

End-of-life (EOL) care of kidney cancer patient has two possibilities depending on the cancer stage. For stages 3-4, EOL means precisely “until the end”, for the rest of their life. For stages 1-2/3, surveillance is continued for five years after which, if no symptoms appear, the patient is declared cancer free. If symptoms appear within the control period, the patient begins treatment again, and this process of re-diagnosis is usually more efficient than for people without cancer history. If the symptoms appear after the cancer free declaration, the cancer care cycle starts from the beginning. Based on these, the kidney cancer patient journey for the EOL care phase is modelled as in Figure 10.

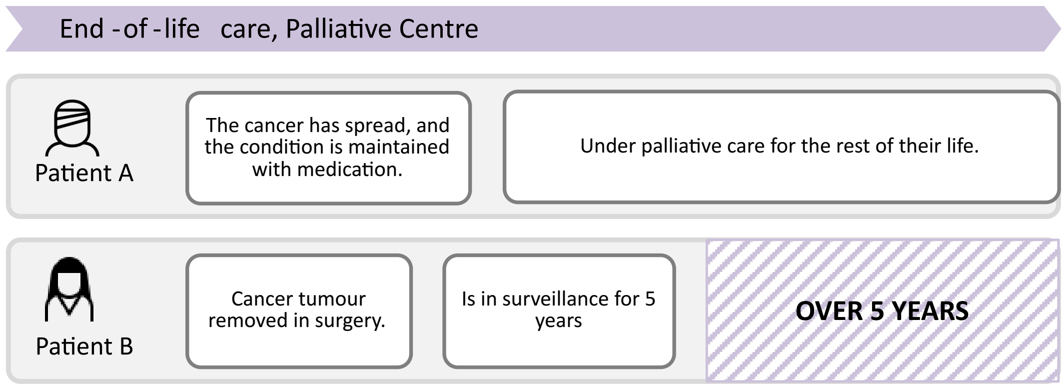


Figure 10 CJML model of end-of-life care

4.4.6 Deviations in the patient journey

Deviations in patient journeys are an essential part of their nature as each one is eventually unique. Typical deviations to care journeys can be instances of disruptions. For example, if the patient forgets their appointment, a report on missing the meeting should always be recorded in the EHR system. Therefore, clearly indicating the missed appointment in the process model is also crucial. In the CJML patient journey such events are visualised by crossing over the planned action or touchpoint (see example in Figure 11 below).

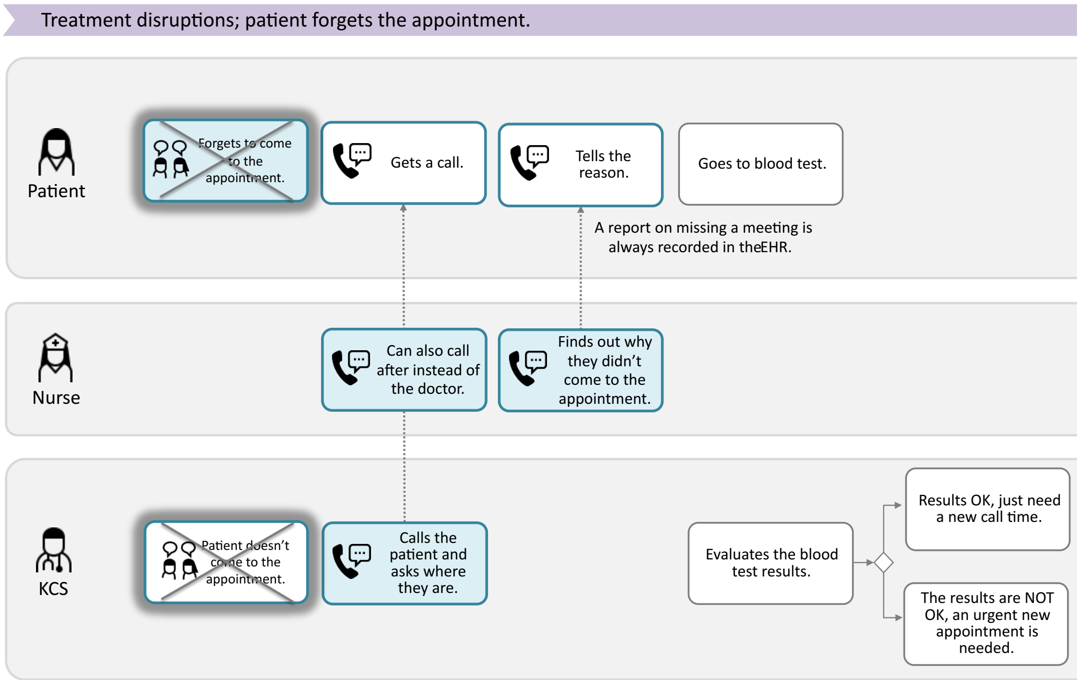


Figure 11 CJML model of disruption: Patient forgets the appointment

4.5 Initial proposals for further development

While CJML is intended to be a user-friendly (Halvorsrud, Haugstveit, et al., 2016) and easily interpretable process modelling language, its current simplicity occasionally necessitates assumptions and adaptations that deviate from established guidelines. Accordingly, this section outlines the modifications and limitations initially applied and discovered during the modelling and provides propositions for future improvement. These serve as a basis for evaluations (4.6), and final proposals can be found in section 4.7.

As CJML is constructed to represent the end-user perspective, its strengths reflect this focus. The language allows easy presentation of information flow at key contact touchpoints and across the process. This is especially important in cases of disrupted communication, where bringing a customer's experience to the forefront can provide meaningful insights. CJML's overall clarity and accessibility are significant advantages, yet these same features include limitations. The flexibility of the language can lead to ambiguity where users rely on their own interpretation and judgement. In turn, the unstandardised use of elements can result in incorrect modelling practices and inconsistent understandings among different users regarding care events and the distribution of information within and between them.

Many of CJML's elements are already inspired by other modelling approaches (Halvorsrud et al., 2023) but the collaborative refinement of the language is still essential. Inspiration from other, more developed modelling notations, such as BPMN, is therefore encouraged (Cassidy et al., 2022).

BPMN offers valuable features that can inform the continued development of CJML. For instance, BPMN allows non-linear, temporal sequences flows and supports creating alternative visualisations for complex, multi-producer settings. It also introduces modularity using sub-processes, allowing for processes to be broken down into manageable blocks. Finally, BPMN's capacity to tailor visual detail to specific stakeholders demonstrates the importance of adaptable modelling in multifaceted environments. For instance, the level of detail can be chosen for different users, and the linearity of a timeline can be adjusted for simplification purposes.

Figure 12 presents an illustrative example of a complex event where further developing CJML is required. The scenario describes a situation in which the patient seeks help, either by calling or messaging in a telemedicine system. Depending on the criticality of the symptoms, the patient's situation may be referred to a nurse from the call centre or from the message conversation. In this case, the timing of interactions is less relevant than the distribution of responsibility among providers, which needs to be accurately visualised.

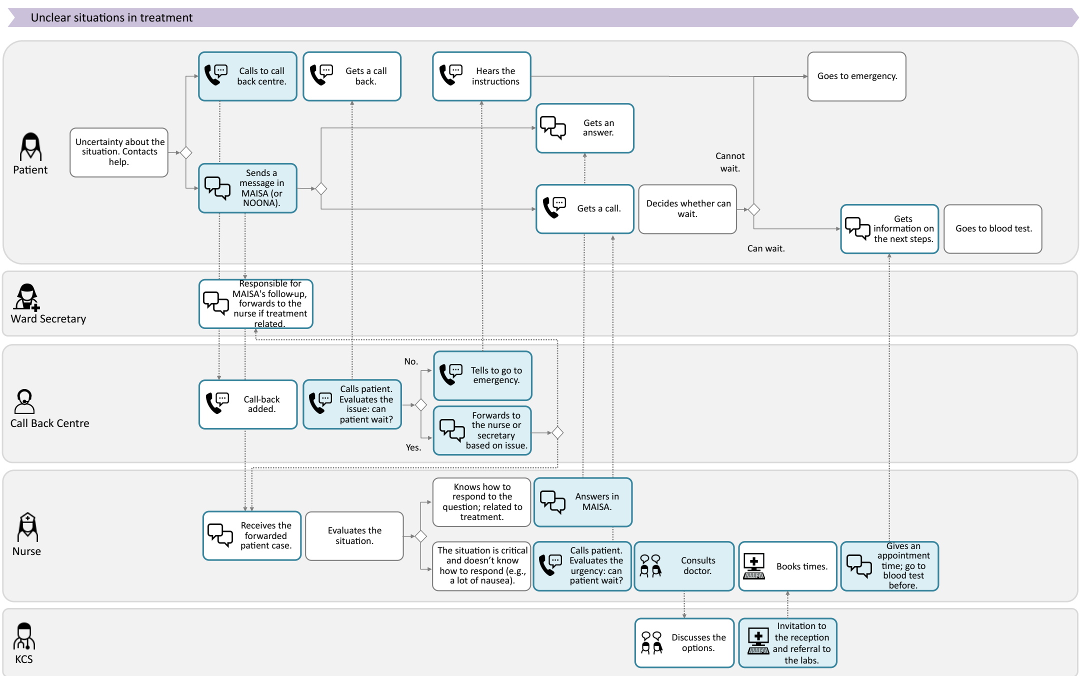


Figure 12 CJML example model of a patient that has a worsening condition, needs assistance and has several options available for communicating with HCPs.

4.5.1 Decision points

Accurately representing decision points requires further development, as the current journey network diagram guidelines do not officially support them. Currently, decision points can only be used in the journey diagram approach. However, their integration is essential for modelling any planned patient journey in the network diagram. Likewise, the current notation doesn't provide a method to indicate inclusive decisions, when *this or that* are both equally valid options. In BPMN, this is indicated by different gateways: the diamond object includes an 'x' for exclusive decisions, 'o' for inclusive and '+' for parallel. Gateway elements can help in directing the flow of complex cases, and including different versions indicates whether one or multiple routes are chosen.

In this study, a modified decision point visualisation was used regardless of whether the options were inclusive or exclusive. Figure 13 includes examples of both current options: an inclusive decision is illustrated when the patient chooses how to contact help (any channel is acceptable), while later, exclusive decisions are made by both nurse and patient – the nurse either knows how to help or does not, and the patient either waits for help or moves on. Alongside, the improved versions are included. Their purpose is to include more information and depict a correct sequence of events: decision happens before the flow divides to two.

However, including decisions in network diagrams led to multiple vertical message flows ending up "behind" other elements in the model, which can be seen to lower its clarity. Further improving decision points may require more information on the nature of decision but should offer guidelines for handling overlapping visual objects. This was discussed in the evaluation workshops and a final proposal can be found in Results (4.6).

The patient journey most likely only follows one of the available options at each decision point. However, if the care plan is shared to the patient beforehand, journey modelling should enable the patient to see the upcoming options and prepare for them accordingly. Parallel journeys are a special case that should be considered in later studies.

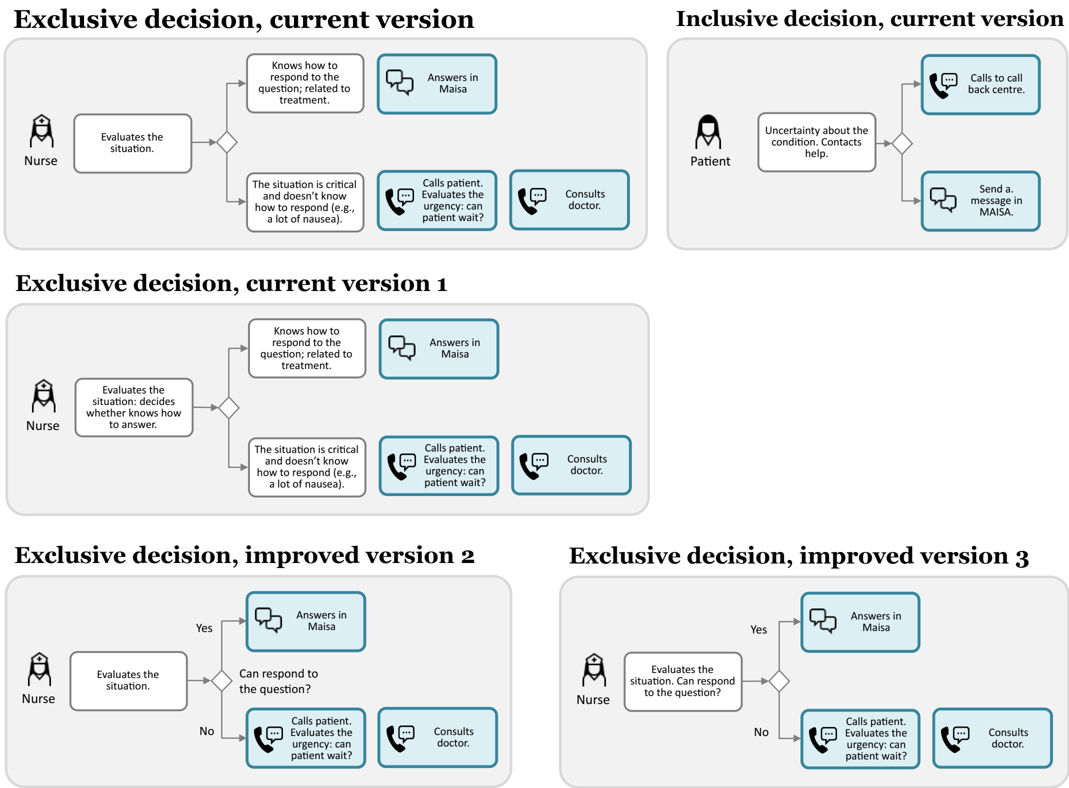


Figure 13 CJML decision points, current and improved

4.5.2 Data object reference

To better emphasise points that require additional information or evidence, the language should include some kind of *knowledge and information storage element*. Currently, CJML supports visualising the retrieval and upload of information via a separated lane for EHR systems. However, in the context of a large network diagram, this approach is not functional and can make the description more confusing.

Data collection visualisation for these cases is strongly supported by other languages. For example, BPMN uses graphical elements like *data object* and *data store* to underline the high dependency of data flows, even though in reality the flows are much more complex, as noted by Zerbato et al. (2015). Providing similar visual tools to CJML would improve communication and understanding between different stakeholders.

In CJML, the retrieval or upload of data can be visualised by referencing a **data object**, as can be seen in Figure 14. Since CJML includes icons for different systems, these can be used to more clearly indicate which system is included.

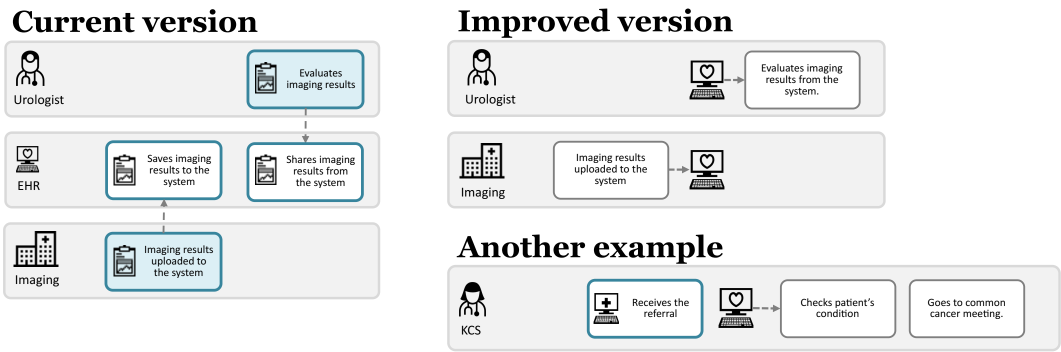


Figure 14 Data object reference, current and improved

4.5.3 Temporal, non-linear timeline

Integrating multiple stakeholders into the swimlane visualisation proved challenging, and maintaining an accurate left-to-right timeline was sometimes impractical. In such cases, efforts were made to include relevant insights and depict a realistic sequence of events as well as possible.

To reduce repetition and improve clarity, some flows were directed temporally "backwards" in the model, moving right-to-left. In Figure 12, this happens after the decision in Call-back centre. While this breaks the consistency of a left-to-right timeline, it could support better overall understanding. Touchpoints still indicate the double-sided, mutual interaction, and therefore events can be assumed to be happening simultaneously despite not being correctly aligned vertically.

Most users expect a left-to-right ordering in process models, but certain situations require more flexibility. For this reason, CJML should support **temporal, non-linear timelines** to simplify the representation of care and better reflect the reality of care processes.

4.5.4 Angled connecting objects

In some cases, message flows overlapped, which made it harder to follow the visualisation. To solve this, **angled connectors** were used **to show the direction of sequence and message flows** more clearly. Although this is not formally supported in CJML, it was found to facilitate readability during modelling. See examples of angled connecting objects in Figure 15 below.

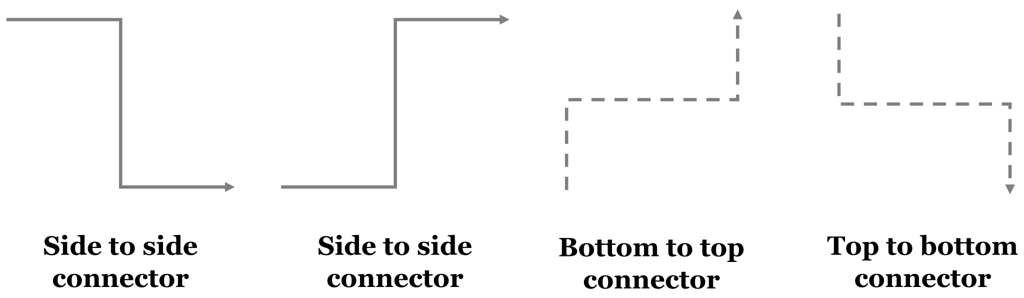


Figure 15 Angled connecting objects, modified

The simplest justification for the use of angled connecting objects is clear: some communication touchpoints do not occur simultaneously. An example of this is given in Figure 16: letter does not arrive at the same time as sent. The current version is therefore giving the wrong illusion of the timeline of events.

CJML should clearly define whether angled connecters are accepted or not. The purpose of angled flow connectors is present in other cases too, such as the complex example in Figure 12, p. 75. They support visualising the flow in complex care events by directing the flow both "further" (like in Figure 16) and "back" (like in Figure 12).

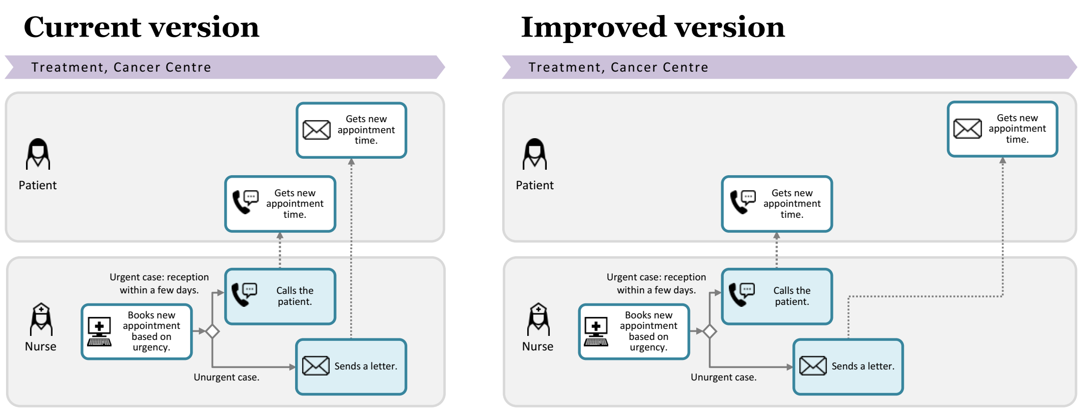


Figure 16 Message flow, current and improved

4.5.5 Looping mechanism

Looping was another modelling challenge. It is needed when a part of the process structurally stays at the same phase until a condition is met, such as during the treatment phase while trying to find a working medication. **The looping mechanism** helps to reduce unnecessary repetition in the visualisation. Logically, looping mechanism includes conditional repetition: the process remains in the same step until something is complete.

One simple way to show a loop is to use a text box, e.g., “Repeat Post-Treatment Survivorship Process until medication works”. Another way is to use icons within the process to mark the looping (e.g., circular arrow icon). A third option is to direct the flow back to an earlier step if conditions are not met.

These looping methods are closely linked to non-linear timelines and angled connectors. Repeating parts of a journey adds complexity, but clear visual solutions can help manage it. Illustrative examples of each are shown in Figure 17.

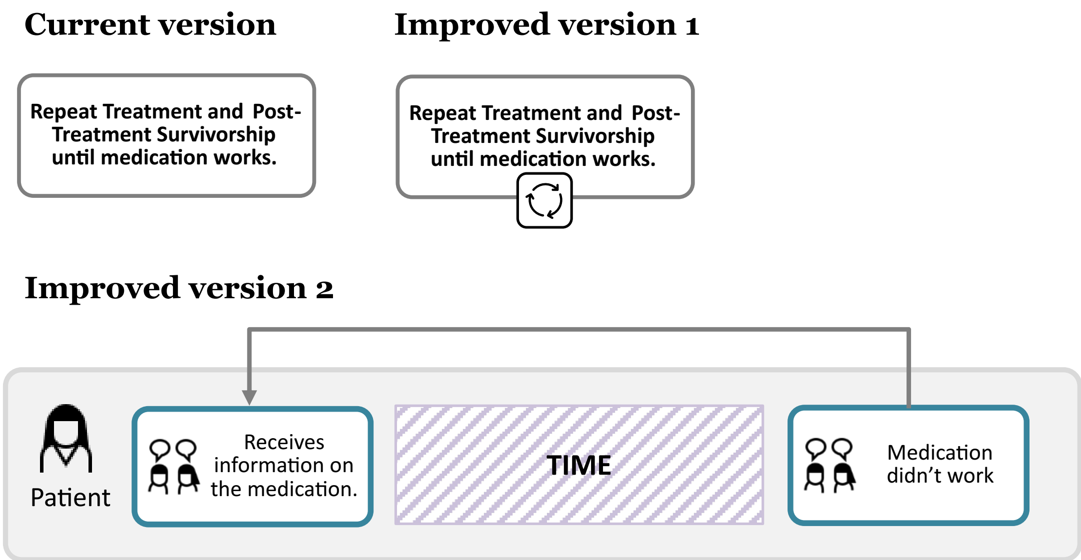


Figure 17 Looping mechanism, current and two improved versions

4.5.6 Modularity and Sub-processes

Including **sub-processes** in CJML would allow for the subdivision of a complex patient process into smaller, clearer phases. Such modularity would help visualise each part more clearly and improve the overall structure.

The cancer care process includes very distinct sequences of actions, such as treatment planning, treatment administration, surveillance of treatment and follow-up care. These can be modelled more effectively as separate sub-processes, helping different users focus on the parts most relevant to them. Figure 18 shows a proposition for the visualisation of modules at the top level of the process.

The proposed visualisation of a sub-process is inspired by the sub-processes approach of BPMN and uses a similar approach. A rectangular box is used to represent the sub-process, and its label indicates the high-level content (e.g., “Diagnosis” or, more specifically, “First meeting with the nurse”). The box includes a small plus sign (+) at the bottom, suggesting that the box can be expanded to reveal the steps inside. Figure 19 illustrates the suggested design.

The aim is to develop a clearer and more usable view of complex care events by allowing modular visualisation within CJML. This expanded view could benefit from further improvement, and the evaluation phase of the study considered what kind of information these sub-processes should contain.

Figure 18 Processes as sub-process modules, current and improved

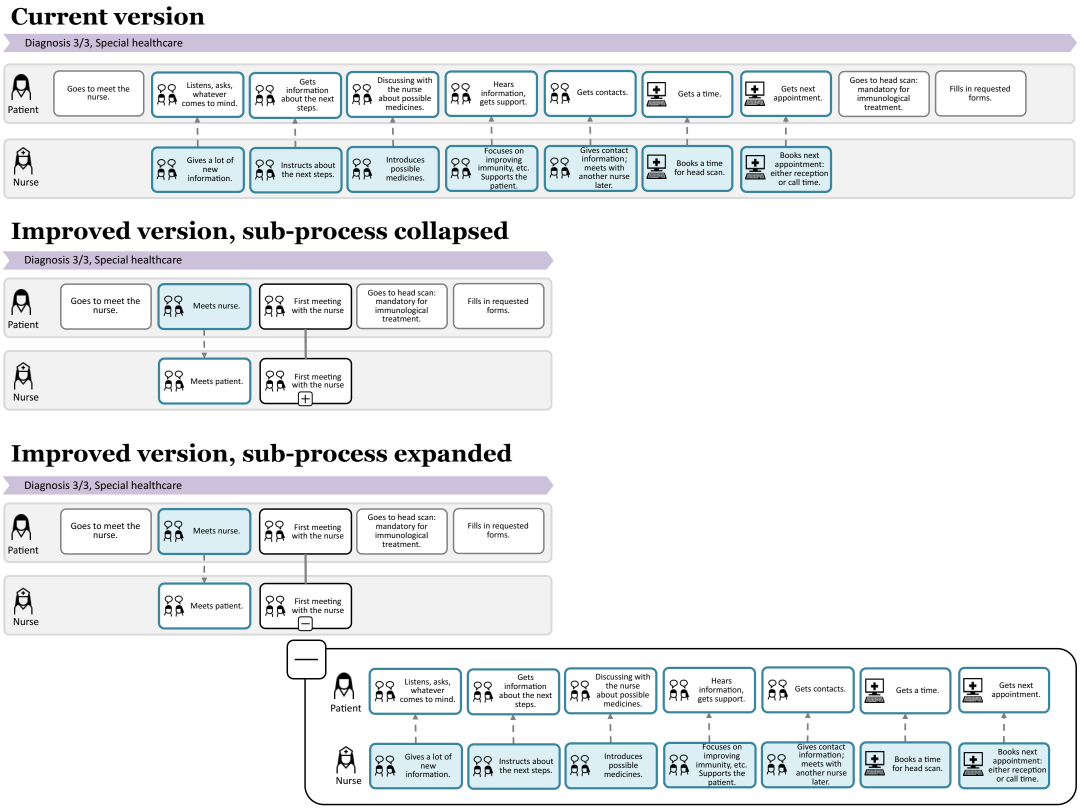


Figure 19 Meeting with the nurse as a sub-process, current and improved

4.5.7 Call activity

In the workshops, certain activities like blood tests and scans were mentioned, yet these involve significantly more steps than what is visualised in the model. While visualising every detail is not always relevant from the care pathway perspective, particularly for providers for whom these are routine procedures, these routine events become familiar events for patients as well. Patients also encounter events that are not directly linked to their care but can significantly affect it. For instance, renewing a patient's Kela reimbursement status is essential for continued access to subsidised prescription medication. Such special cases are included in the Appendix C.

To accommodate this, a **call activity** can be used to refer to a process that has already been defined earlier. For example, the same test process can be reused without repeating it in the visualisation. This approach would offer a way to maintain clarity while allowing the process to be expanded when necessary. This proposed improvement is also inspired by BPMN which uses a similar approach.

In the proposal in Figure 20, the call-activity is visualised similarly to a standard action, but with specific visual cues: a “rewind” style icon is added to indicate reuse of a previous process, and the outline of the action point is emphasised in black to distinguish it from regular action points.

Like sub-processes, a call activity can be expandable or provide additional detail depending on the model user's perspective or needs. For instance, a clinician may wish to access clinical subtasks, while a patient may benefit from a more general explanation. BPMN enables the development of several variations of a single process that is tailored to different user needs (Combi et al., 2017). Similar flexibility should be considered for CJML. Figure 20 illustrates a visualisation of a call-activity from the patient-central perspective but would allow access for further details by expanding the process.

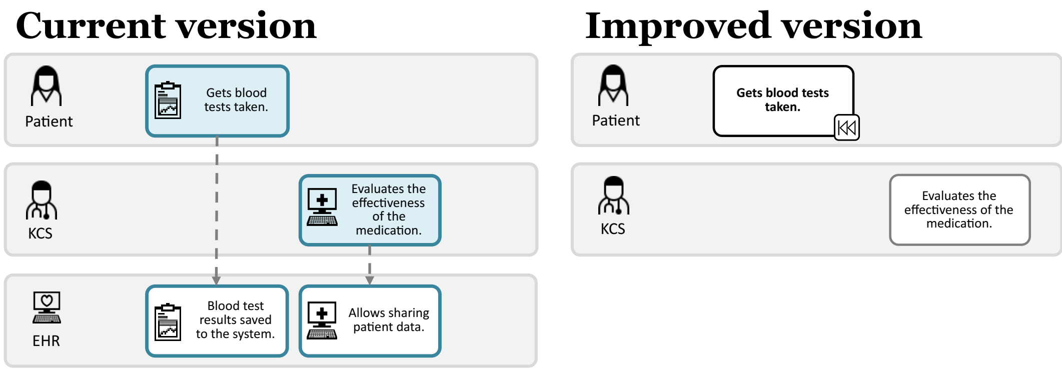


Figure 20 Call-activity, current and improved

4.5.8 Discussion point

The final, proposed improvement concerns the visualisation of discussions and shared decision-making. Currently such interactions are represented in CJML through touchpoints, as they require active contact between the patient and care provider. However, in patient-centric and co-created care models, collaborative decision-making is a distinct and meaningful event that deserves a clearer, distinctive visual representation.

To address this, a dedicated visual element called a **discussion point** is proposed. The element is based on the visual features of a communication point but is modified to reflect its unique characteristics. First, connector points in both directions indicate the mutual exchange of information. The communication channel is kept as it remains relevant. Second, the outline of the shape is changed to the grey tone used in action points, to underline that a) it is not a standard communication point, and b) that there is no single sender or receiver of the information. Third, the fill of the object remains blue to emphasise that both parties are participating and sharing information.

An illustrated visualisation for such a point is presented in Figure 21. This visualisation explicitly highlights the collaborative nature of the event, where the patient is also an active participant in the decision-making process. Incorporating such a visual element supports the modelling of shared agency and mutual engagement, both of which should be essential in current patient-centric care practices.

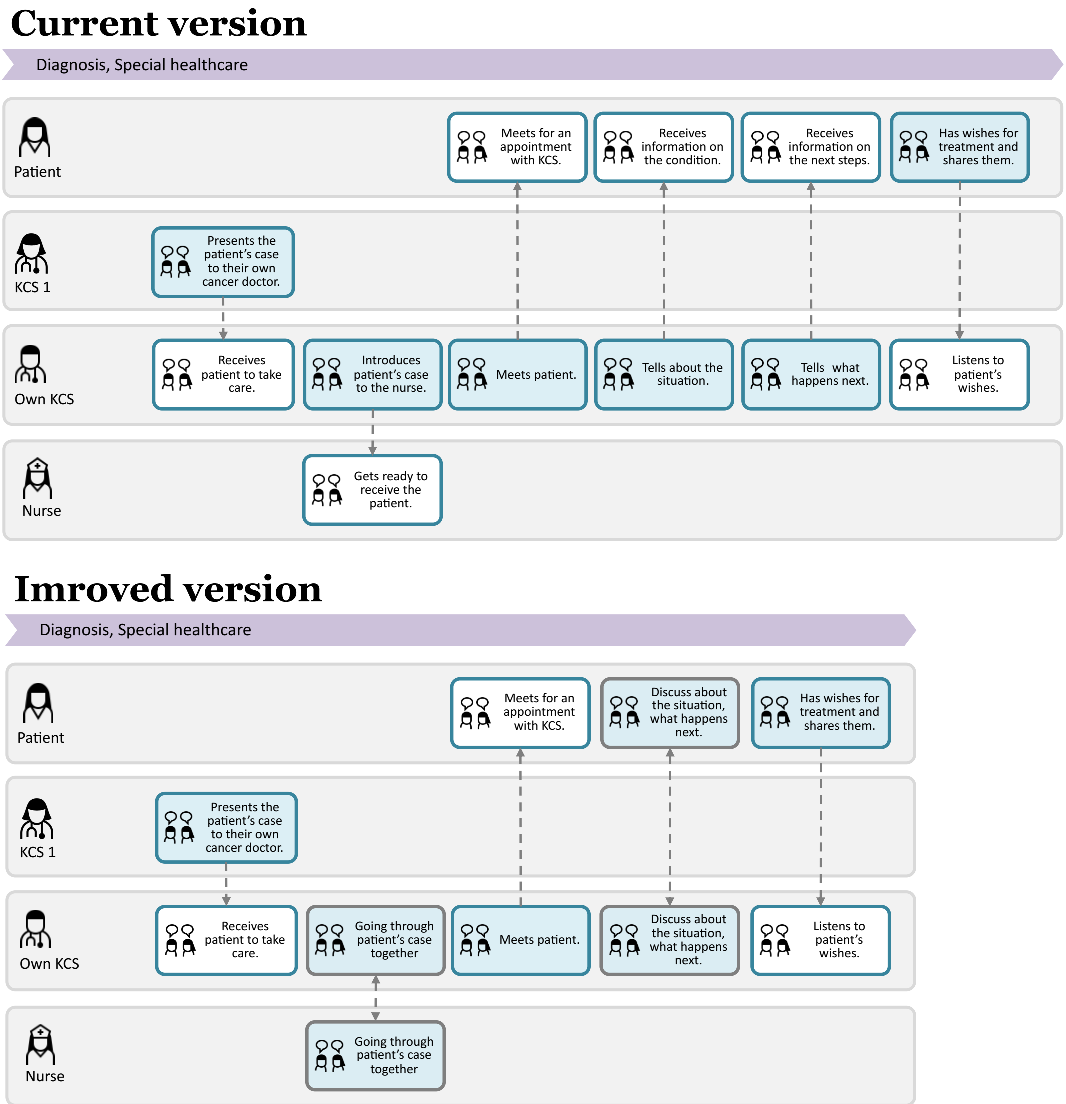


Figure 21 Discussion point, current and improved

4.6 Results of demonstration and evaluation

The evaluation workshops were highly informative and useful. Next, the results of both are shortly presented separately and the modification made in between are included.

4.6.1 Results from workshop 1

Altogether the demonstrated models were evaluated greatly representing planned and actual elements of kidney cancer patient journey. Especially, the example of complex modelling in Figure 12 (p. 75) provoked discussion. Its current modelling format was not considered sensible, and experts did not support the idea of breaking the timeline, not even temporarily. Although the complexity of the situation was acknowledged, according to them the situation must be simplified by other means. The improvements should be consistent in simplifying the process picture and reliably provide better visualisation.

The performance of evaluated proposals is summarised in Table 7. An 'x' indicates that the evaluation criterion was considered fulfilled but based on discussion only, without a formal vote. For priority mapping, participants could mark the proposals they considered highest priority with a '+' and second highest with a '(+)'.

Table 7 Evaluation results of the evaluation workshop 1

Proposed improvement	**Accurate**	**Clear**	**Benefits the user**	**Reliable**	**Easy to use**	**Complete**	**Priority**
Decision point	x		x		x	x	+++
Temporary, non-linear timeline							
Looping mechanism			x		x	x	++
Angled connector	x	x					
Modularity	x	x	x	x	x	x	+++
Sub-processes	x	x	x	x	x	x	+++
Call-activity						x	(+)
Data object		x	x		x	x	(+)(+)
Discussion point	x	x	x	x	x	x	+++

4.6.2 Further improving the proposals

The proposals that required some level of further developing were modified after the first evaluation round. This concerns the following elements: decision-making and call-activity.

Decision point improvement concerns the specification of the element. Decision point should always indicate the made decision prior the branching of the pathway, so visually before the diamond shaped gateway object. This is in accordance with the timeline of activities and provides user the possibility to understand exclusive cases, its options and how they relate to the made decision. Figure 22 illustrates this addition, with two alternatives for the visualisation.

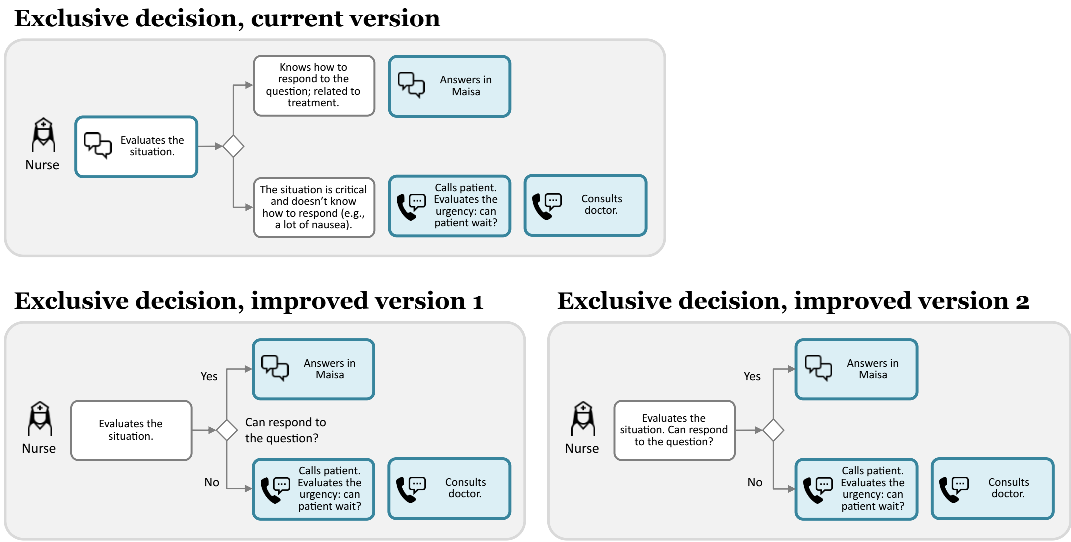


Figure 22 Exclusive decision point, current and improved

Repeat action (previously defined as call-activity) can be used to refer to an activity that has already been defined earlier and is stored externally as separate CJML diagram. It works as a subtype for sub-processes. Figure 23 gives an example how a repeating event could be defined. By this, the same test activity can be reused without repeating the whole sequence of touchpoints. This approach would offer a way to maintain clarity and doesn't exclude the repetition of touchpoints if wanted. The visualisation of the repeat action is slightly modified: "rewind icon" is changed to back directing arrow. Distinguishing feature from the looping mechanism is that, repeat action refers to a separate process block whereas looping mechanism occurs within the step. Repeat action is a structural reuse and looping mechanism is more of a conditional repetition.

Like sub-processes, a repeat action can be expandable or provide additional detail depending on the modelling user's perspective or needs. The distinction from sub-process relates to the decreased amount of repetition: sub-process can be modified for multiple cases, but ideally the repeat action is unmodifiable once marked as one. Alternatively, once modified, it will affect all the cases it has been included in and repeats the action in accordance with the modified version. Repeat action can still refer to an activity that includes sub-processes. The possibility of integrating sub-processes and repeat action as one element is to consider in future validation.

As noted, CJML should allow for modelling different iterations of the same process phase. For instance, an HCP may wish to access clinical subtasks, while a patient may benefit from a more general explanation. Figure 23 illustrates a visualisation of a repeat action from the patient-central perspective but allows access for further details by expanding the process.

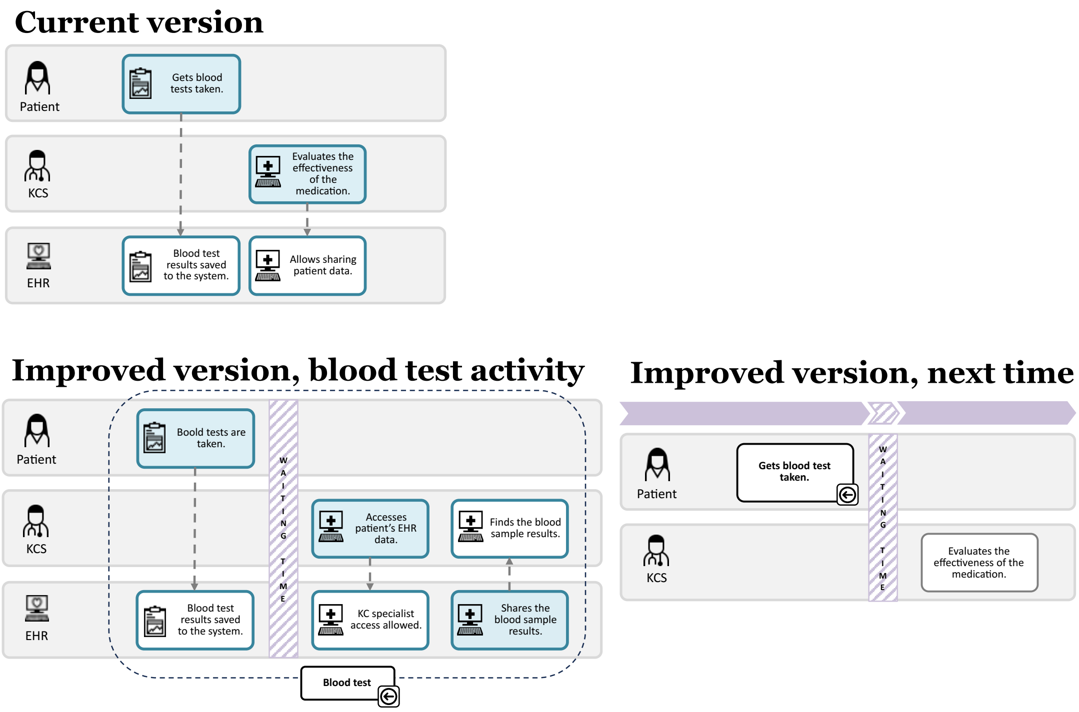


Figure 23 Repeat action, current and improved

4.6.3 Results from feedback on CJML usage

Between the workshops, the developer of CJML offered feedback on used visual notations and proposals. Based on this, proposals on temporal, non-linear timeline and angled connectors were proven to be based on faulty information: despite no guideline on their use is written, they are currently used in the CJML. Non-linear timeline is for temporal use only and always depicted by a time icon or in the additional comment lane. Angled connectors can used for the exact case as provided in Figure 16, on page 79. This validated the identified need as correct. As the angled connector included a proper modelling example, it was still included in the evaluation workshop for comments and discussion. However, both were excluded from the priority voting as they are already supported.

4.6.4 Results from workshop 2

Table 8 summarises how participants evaluated each proposal against seven predefined criteria, offering insight into their perceived modelling accuracy, clarity, user benefit, reliability, usability, and completeness. The responses provide insight into the perceived strengths and limitations of each extension.

Table 8 Results of criteria evaluation from the workshop 2

Proposed improvement	**Accurate**	**Clear**	**Benefits the user**	**Reliable**	**Common need**	**Easy to use**	**Complete**
Decision point	5	6	4	4	4	3	3
Looping mechanism	1	0	5	1	5	1	5
Angled connector	4	2	5	4	4	2	5
Modules	3	4	5	3	5	4	5
Sub-processes	5	4	6	4	6	5	6
Repeat action	2	2	5	3	4	3	2
Data object	0	0	4	2	5	1	5
Discussion point	1	3	1	1	0	1	2

Table 9 summarises how participants assessed the overall maturity of each proposal. Each participant selected one of three options indicating whether a proposal was ready for further development, promising but requiring iteration or not currently relevant or beneficial. Note that voting was optional.

Table 9 Results of implementation readiness from the workshop 2

Proposed improvement	**Useful and ready for further development**	**Promising but requires iteration**	**Not currently relevant or beneficial**
Decision point	3	1	0
Looping mechanism	0	6	0
Modules	2	0	0
Sub-processes	3	2	0
Repeat action	1	5	0
Data object	0	5	0
Discussion point	0	3	2

In the final step of the workshop, participants marked the proposals by voting for the ones they considered most valuable. They also ranked their selections in order of importance. Table 10 presents the total number of votes and the ranking outcomes, highlighting which proposals were perceived as most critical for further development.

Table 10 Results of prioritisation from the workshop 2

Order of importance	Proposed improvement	Most valuable (total votes)
1	Sub-processes	6
2	Modules	2
3	Decision point	3
4	Looping mechanism	1
5	Data object	2
6	Repeat action	2
7	Discussion point	1
-	Angled connector	-
-	Temporary, non-linear timeline	-

4.7 Proposed developments to CJML

Following the demonstration and evaluation, all proposals presented during the workshops were reviewed again in light of the expert feedback. Both workshops consistently identified sub-processes as the top priority, meeting most of the evaluation criteria and considered ready for implementation by half of the experts (3 out of 6) in workshop 2. While all proposals will likely benefit from further user testing, Table 9 indicates that the current visualisations of only decision points and sub-processes are the most mature and ready for continued development. In contrast, although the looping mechanism was recognised as promising, particularly as a common need and a missing feature in CJML, the proposed version still requires further refinement.

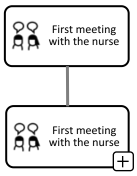
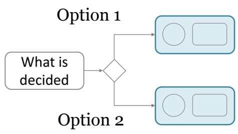
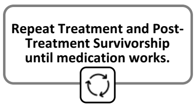
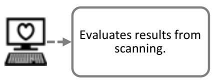
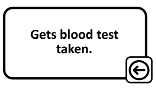
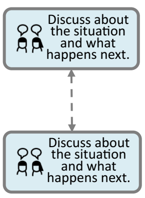
Most of the proposals were considered promising but in need of further iteration. These refinements involve either practical testing or improvements to visual representation. For example, the data object was evaluated as beneficial for users, a common need, and as addressing a relevant gap in CJML. However, its reference must be clearly defined to avoid confusion about what the object is used for. One suggested solution is to place the EHR system in a separate swimlane and use the same icon when referencing the data object.

This approach helps minimise overlapping sequence flows while maintaining the visibility of data interactions within the process model.

As mentioned, non-linear timelines and usage of angled connectors is currently approved in CJML, even though clear definitions are still missing from the guidelines. The discussion in expert workshop considered them both and emphasised the importance of clearly indicating any timeline break, either through time expressions or visual markers. When angled connectors are used, particularly if they disrupt temporal sequence, a clear indication of time is required to preserve clarity. In the example shown in Figure 16 (p. 79), this this could be addressed by placing a time indicator before the "Gets a new appointment time" touchpoint, which represents the receiving of the letter. In this case, the waiting period is only experienced by the patient and may otherwise remain invisible. While both features were seen as useful, they require further refinement to avoid misinterpretation and to ensure consistency in use.

The Table 11 includes summarised expert validation, includes priority in two categories, gives final versions of the proposed developments, their value propositions, and serves as a resulting output of this study.

Table 11 A compiled table of the evaluated improvement proposals

Development	Visualisation	Added value	Expert validation	Priority
Sub-processes		Enables detailed breakdown of complex stages while maintaining a clear overview.	The usability of sub-processes is high, and it enhances the modelling greatly. The scope and level of detail must be clearly defined: what is the broadest and most precise level of detail included, and for which user.	1
Modules		Encourages structured and reusable modelling.	The modules, reusable building blocks should be built as sub-processes. The modules are not to be confused with process phases that are already part of CJML	1
Decision point		Enables clear visualisation of decision points and branching paths in network diagram.	If something is decided, it must be underlined before the decision point. Using different visual markers (e.g., 'x' for inclusive decisions) is recommended and should be explored further.	1
Temporary, non-linear timeline		Allows simplified process model for alternative care paths.	Should be included in the guidelines. Breaking the timeline should be always indicated by a separate note and expression of time.	1
Angled connectors		Enables clear and accurate depiction of the process flow, even in complex cases.	Should be included in the guidelines. If angled connector breaks the timeline, an expression of time should be included. Further testing is needed on how this is depicted on only one of the swimlanes.	1
Looping mechanism		Supports representation of iterative actions and repeated behaviours within a process.	Needs further testing on more cases to improve clarity and reliability but overall, the need for the improvement is high.	2
Data object		Provides a way to visualise and track uploaded and retrieved data within process steps.	Indicating upload and retrieval of data is a relevant need. A suggested test is to combine the data object and EHR in a separate swimlane, using the same icon but without a sequence flow between them.	2
Repeat action		Facilitates repeat of standardised processes by referencing external process logic.	Requires the process presentation as modules. Visualisation needs further refinement to avoid confusion but overall, noted promising.	2
Discussion point		Enables a visual representation of a shared interaction point to capture the collaborative nature in patient-centred care.	Visualisation is clear as it provides more realistic representation of interaction. A common need in all process modelling languages but clear usage guidelines are necessary and challenging to define. Further research and testing are recommended.	2

5 Discussion

This chapter summarises the research results, responds to research questions and analyses how well they were answered. Part 5.1 concludes elements of the typical kidney cancer patient process. Part 5.2 differentiates the studied modelling languages. Part 5.3 explores the proposed improvements and to which the results might be relevant. Findings from both literature review and empirical study are discussed on the research questions. To conclude, this chapter gives a summary of discussion in part 5.4 and reflects on the study's strengths and limitations in 5.5.

5.1 Typical Kidney Cancer Patient Process

This study began by identifying relevant dimensions and objectives that shape the kidney cancer care process, combining perspectives from clinical care and process modelling. These considerations informed the construction of a representative patient journey, forming the basis for subsequent modelling work.

In healthcare, structured patient *pathways* help coordinate care across professionals and services. These typically follow clinical guidelines and process steps but are also influenced by the patient's individual needs and circumstances. Patient pathways encompass both the clinical and organisational aspects of care (Eklund et al., 2024; Vesinurm, Sylgren, et al., 2024). However, the concept of a patient *journey* adds further depth by introducing the experiential and behavioural dimensions of the patient, explicitly incorporating their experience, engagement and role at different stages (Bogale, Vesinurm, et al., 2024; Følstad & Kvale, 2018). Modelling this journey requires tools that can incorporate not only clinical tasks but also human interactions, experiences and knowledge transitions in care.

Cancer care is a particularly relevant context for this approach due to its complexity. Complexity arises from the need to balance medical, psychosocial and organisational factors (Plsek & Greenhalgh, 2001; Vehkamaki et al., 2024), all of which evolve over time. Kidney cancer care exemplifies this: patient journeys span multiple care stages, involve various healthcare professionals (HCPs) and require frequent re-evaluation. Furthermore, complexity is inherent in patient journeys where frequent non-standard decisions are required, and where uncertainty affects both the process and the expected outcomes (Vesinurm, 2025).

Workshop findings supported this view. Interviews and modelling sessions with kidney cancer experts confirmed the multidimensional nature of the care process. Transitions, coordination across producers, information flow and multiple steps echo earlier studies (Anhang Price et al., 2010; Taplin & Rodgers, 2010; Zapka et al., 2003). Although clinical decision-making was found to be collaborative, it was still primarily driven by HCPs. Patients had limited visibility into care plans or the rationale behind choices, which weakens their ability to engage meaningfully.

This raises an important tension: while patient-centred, co-created care is recognised as desirable (Cassidy et al., 2022; Halvorsrud, Kvale, et al., 2016; Laukka et al., 2025), its realisation remains limited in kidney cancer care. Without clear frameworks for information sharing and role definition, patient involvement remains passive rather than active and often dependent on the individual initiative of professionals.

Based on these findings, three key characteristics of the kidney cancer patient journey were identified:

1. **A complex, interactive multi-producer environment**, where care is delivered across several institutions and professional boundaries.
2. **Decision-making dominated by medical expertise**, with limited implementation of co-created or patient-directed care, despite its acknowledged benefits.
3. **Information flow as a critical success factor**, affecting every stage of care and influencing transparency, continuity and the patient's sense of agency.

In conclusion, understanding the kidney cancer patient journey requires acknowledging its multi-level complexity. Any modelling effort that seeks to support co-creation and automation must address these organisational, relational and cognitive dimensions. These insights inform not only the selection and use of modelling languages but also their future development, particularly in representing roles, responsibilities and the evolving nature of patient participation.

5.2 UML, BPMN and CJML in Modelling Patient Journeys

The second research question aimed to determine the distinguishing factors of Unified Modelling Language (UML), Business Process Model and Notation (BPMN) and Customer Journey Modelling Language (CJML) in modelling the key characteristics of a typical kidney cancer patient process. To do this, the study examined the suitability of each modelling language based on their ability to represent key patient pathway elements, such as decision points, information flows and patient involvement.

UML is a general-purpose, software-centric modelling language that was found often used in clinical pathway modelling. UML activity diagrams effectively represent workflows, while use-case diagrams can assist in classifying hospital departments and their roles. UML has been utilised for comparative analysis of processes across institutions and performs well especially in defining roles and responsibility (Shiki et al., 2008). For illustrative development, web-based UML tools exist but their usability varies when tested on clinical pathways (Pahl et al., 2015). While it is useful for illustrating activities and data flows (Askari et al., 2013), it lacks strong organisational structure representation and has limited application in patient-centred modelling (Askari et al., 2021).

BPMN is a business-oriented approach widely used in healthcare to model workflows. It is considered more intuitive than UML, particularly for process automation and optimisation. BPMN supports modularisation via call-activities, which benefit repetitive tasks such as blood tests. Role differentiation using pools and swimlanes is advantageous in multi-producer environments like kidney cancer care (Combi et al., 2017). BPMN can also integrate with other approaches, such as Decision Model and Notation (DMN) to enhance decision-making representation (Pufahl et al., 2022). However, BPMN struggles with variability and uncertainty in patient pathways (Burwitz et al., 2013), lacks representation of temporal relationships and behaviour (Tehrani et al., 2013), and is complex to implement effectively (Scheuerlein et al., 2012).

CJML as a human-centred modelling approach designed for a broad audience, CJML does not require prior modelling expertise and is found user-friendly (Halvorsrud, Haugstveit, et al., 2016). It captures touchpoints in patient care, interactions and experiences, making it particularly suitable for patient-centred kidney cancer pathways. Diagrams depict planned versus actual pathways, and network diagram illustrates interactions between patients and care providers. CJML supports user experience (UX) representation and patient feedback integration (Halvorsrud et al., 2014). It is especially strong in highlighting the end-user, patient perspective and actual journeys, also through deviations from the planned (Halvorsrud et al., 2023). However, as a developing language, CJML requires adaptation to fully accommodate complex healthcare workflows and decision-heavy medical processes.

The comparison in Table 12 highlights that no single modelling language currently accommodates the full spectrum of needs in complex, patient-centred healthcare environments. UML provides structure and responsibility modelling, making it useful for understanding responsibilities and system interactions. BPMN is a highly developed and flexible language, particularly effective in clear role-based workflows and module presentation. It is well-suited for multi-producer environments and decision-making, especially when used alongside other notations. CJML, while still evolving, uniquely captures patient experience and information flows, but currently lacks mechanisms for detailed decision logic and managing complex, distributed processes.

Table 12 Summarised comparison of UML, BPMN and CJML

Feature	**UML**	**BPMN**	**CJML**
Focus	System-centric	Business-centric	End-user-centric
Strength	Captures workflow logic, system interactions and responsibility	Optimises process efficiency and role separation, advanced modelling notation	Highlights patient journey and interactions, user-friendly
Weakness	Not designed for patient-centric modelling, requires modelling expertise	Limited support for variability and human behaviour, requires modelling expertise	Needs adaptation for medical decision-making and complexity
Best use	Clinical workflow analysis, responsibility identification	Healthcare role/process management, compatibility with other languages	Patient-central pathways, information transfer

The unique characteristics of the sector, such as information asymmetry, co-creation of health, fragmented and specialised structures (Vesinurm, 2025), pose challenges that exceed the design intentions of general-purpose modelling tools. These findings suggest that future modelling language development in healthcare should not aim to find a universal solution, but rather to synthesise essential features across languages, tailored to the unique, variable and multi-producer nature of health service delivery.

In line with Design Science Research principles, this study developed and iteratively refined CJML through expert workshops, responding to a "heretofore unsolved and important business problem" (Hevner et al., 2004, p. 84). The resulting artefact consisted of CJML-based models of the kidney cancer care journeys, which were developed, evaluated and refined. The artefact not only demonstrates the applicability of CJML to complex care processes but also serves as a foundation for its continued development. These future directions, including practical proposals for development and broader validation, are discussed next.

5.3 Evaluating the performance for future improvements

The third research question examined the potential of process modelling, specifically using CJML, to enhance patient journeys. CJML enabled the representation of the clinical decision points, interventions and outcomes, capturing the knowledge of HCPs and supporting the patient-centred approach. Although no patients participated directly in the workshops, the modelling development considered patient-central and co-creation improvements. In the evaluation workshops, nearly all of the proposed development suggestions were considered relevant by the participants, although some were perceived as higher priority than others.

5.3.1 Enhancing patient-centred care through process modelling

Cassidy et al. (2022) encouraged the use of multiple modelling languages, supporting the broader objective of standardisation. While this study focused on CJML, the evaluation of its limitations and strengths implicitly supported such comparative efforts. The improvements were developed based on established methods known for identifying bottlenecks and supporting partial automation, but its limitations in visualising looping or complex decisions, highlighted the need for further refinement. These modelling challenges helped clarify the requirements for effective patient journey modelling.

A key insight of the gathered evaluation was the need to support patient understanding and engagement. Supporting effective decisions and patient proactivity will enhance the quality and targeting of care but in turn these require better capturing and streamlining of the patient journey. Patients often lack visibility into the overall care process, receiving information incrementally. This can lead to a loss of agency and increased anxiety. Sharing phase-specific goals and steps, even without a complete care plan, can enhance patient trust and engagement. Modelling should thus be seen not just as a clinical tool but as a support system for patients, enabling better organisation, continuity of care and emotional resilience. It is not even meaningful to share the entire plan, as uncertainty regarding outcomes is inherent to the complexity of patient pathways (Vesinurm, 2025); treatment is an iterative, evolving process that continuously adapts over time.

This also raises important questions for future research: where should the line be drawn in sharing information with patients? Especially in complex care contexts, patient-centredness should not be mistaken for indiscriminate data dumping. Instead, the goal must be to offer meaningful, comprehensible and timely information that supports the patient, and does not overwhelm. Exploring these boundaries could guide both the development of modelling languages and the broader design of patient-centred communication strategies.

5.3.2 Modularity, responsibility and the role of automation

Further, the introduction of modularity as sub-processes was considered beneficial in the evaluation workshops. Sub-processes were seen enhancing clarity and manageability of the model. Instead of one extensive model, using sub-processes allows detailed yet accessible visualisations. Modular process segments, such as pre-appointment tests, nurse visits, or decision-making phases, enable patients and healthcare professionals alike to view care as logical, repeatable building blocks. This approach aligns with both Combi et al. (2017) who emphasised the role of modularity in healthcare process design and with principles of service modularity, where distinct service packages can be reused, tailored and rearranged as needed.

The sub-process approach also improves the model's usability for both professionals and potentially patients. Representing the care process as models supports the engagement of patients but helps to regulate visibility as they can have access only to an ongoing phase at a time. Importantly, modelling these phases with sub-processes supports checklist thinking, which patients with chronic conditions may find especially helpful due to limited capacity for cognitive load under stress. This may help them and their families revisit previously covered phases, expand additional information, and prepare for upcoming phases, which supports the idea of sharing actively taking ownership of their own care (Carman et al., 2013). Furthermore, dividing each phase to multiple separate building blocks, sub-processes, can assist in future automation efforts (Andellini et al., 2017; Combi et al., 2017).

Process modelling does not aim to automate the care process entirely: automation should remain as a supportive function, ensuring decisions are grounded in human expertise. Partial automation in the care process can enhance clinical decision-making, for instance, by highlighting relevant patient data or suggesting options (Burwitz et al., 2013). CJML's integration with UML can support selective automation, for instance through data-driven sub-processes that inform decision-making while keeping the final responsibility with HCPs.

The evaluation workshops discussed ways to structure and distinguish standardised and customisable components. At higher levels of abstraction, processes can be automated and generalised, supporting efficiency and consistency. However, as the model is elaborated with more detail, the more the patient's individual needs and preferences must be considered. This reflects the tension between clinical guidelines and patient wishes, which calls for careful coordination where roles and decisions are clearly structured, for instance, as standard, routine and non-routine processes (Lillrank & Liukko, 2004). Process automation can play a supportive role in this structure by streamlining standard and routine tasks, ensuring consistency and efficiency. This allows human actors to focus on the more complex, non-routine elements that demand clinical judgement and attention to patient-specific needs.

Lastly to address the varying levels of patient involvement in the care process, it is important to ensure that process models can indicate responsibility clearly. A recurring theme in evaluation workshop 1 was the visibility of responsibility at different points along the care pathway, especially when patient involvement fluctuates from passive recipient to active participant. Modelling tools such as CJML could benefit from additional elements that highlight who is responsible for the action or decision at a given point.

To support this coordination, it is important to make responsibilities transparent at each stage of care. While CJML already indicates communication responsibility, the language could further benefit from clearer visual representation of responsibility: who is accountable for what, and at what point in the care pathway. Hypothetically, at higher abstraction levels, responsibility could be system-driven and, for example, automatically assigning upcoming tasks to a nurse or patient. However, this is also highly individual as the patient can be a passive receiver of information or actively involved in care. If HCPs prefer not to share care plans with patients, while patients themselves wish to take on a more active role, a conflict arises. Resolving such tension requires mutual trust: professionals must feel confident in patients' engagement, and patients must in turn understand and fulfil their responsibilities. Clarity in role definitions is essential: who acts, when, and what it concretely means for something to be "the patient's responsibility.”

Integrating such role indicators is especially vital in complex care scenarios like cancer, where responsibility often shifts between HCPs and care units. Patients may contact services independently, but responsibility may still rest with the HCP in charge at a specialised unit. A visual indicator denoting responsibility, be it the HCP, the patient or shared, would support clearer expectations and handovers. Given UML’s strength in role definition and responsibility allocation (Shiki et al., 2008), its elements use-case and class diagrams could offer valuable inspiration for developing similar structures in CJML.

5.3.3 Who benefits from process modelling?

Representing complex patient journeys through modelling is not novel but remains essential due to the lack of a universal standard. Care rarely follows a linear trajectory, and patient journey disruptions (PJDs) can significantly affect outcomes (Vesinurm, Sylgren, et al., 2024). Mapping the process helps identify inefficiencies, such as bottlenecks between diagnostics and treatments, which impact both patient experience and resource use. Furthermore, it also highlights opportunities for redesign to improve the overall efficiency of healthcare services (Ju et al., 2017).

To identify and address process shortcomings and PJDs, a deep understanding of both process phases and transitions is essential. This includes knowing what information is required at each step, who has access to it, and how it flows between systems, producers and actors. Process modelling can support this analytical depth by making uncertainty visible and enabling simulation-based exploration of care pathways. Patient journey mapping (PJM) complements this by capturing experiential and emotional dimensions, revealing gaps between patient and professional perspectives (Larsen et al., 2024).

Together, these approaches, detailed process understanding and patient-centric mapping, form a foundation for more effective data-driven care development. Importantly, increasing the use of EHR and other data sources is only beneficial when relevant metrics can be identified and applied purposefully. Without this, data collection becomes burdensome rather than enabling. To meaningfully improve care through knowledge management and data utilisation, both technical expertise and a systems-level understanding of healthcare are essential.

Overall, the inclusion of sub-process and visual role clarity enhance the utility and accuracy of care process models. These features also lay the groundwork for broader applicability in automation and digitalisation of care planning, while reinforcing the patient's central role in managing their journey. Ultimately, detailed and well-structured models should enable deeper analysis, helping to prevent errors and disruptions in both individual and systemic care.

Combi et al. (2017) identified key limitations in BPMN's ability to represent complex care and proposed extensions to address them. However, like many existing tools, their framework assumed modelling expertise that frontline healthcare staff typically do not possess and shouldn't even - their focus should be in providing the care. This reinforces the need for clear, modular modelling approaches that align with clinical realities and can be integrated without requiring specialist skills.

While much of the discussion has focused on technical improvements and patient involvement, it is worth explicitly reflect also on the broader goals of process modelling. Based on this study, it still remains unclear who is the primary beneficiary, healthcare producers, system designers, patients or all of these? Commonly user process modelling approaches, such as BPMN and UML, have identified the primary group clearly but tend to overlook the others. Ideally, modelling acts as a shared language across roles: clarifying workflows for HCPs, improving care continuity for patients and providing tools for policymakers to evaluate service delivery. Achieving this balance requires not only technical precision but also inclusive design thinking. Future development of modelling languages like CJML should therefore be guided by the principle that clarity in care processes is a shared responsibility. While its current orientation is from the end-user perspective, the benefits of improved modelling should extend not only to the professionals involved in care, but especially to the patient.

However, it is also important to critically consider to what extent patients should be involved in the development of a process mapping tool. Based on the context of this study, the primary users of such tools are HCPs and care producers, who could use the models to design and communicate coherent care processes. While process models can support professionals in explaining care pathways to patients, the mapping methodology itself may not hold relevance or practical meaning for patients living with kidney cancer. This relates also to the broader question about the boundaries between useful and burdensome information: how much detail is necessary or appropriate to share with patients, and when does it become counterproductive?

This also invites a broader reflection on the extent of patient involvement in the development of modelling tools like CJML. While patient participation is often framed as inherently beneficial and aligned with the principles of patient-centred care, it is worth questioning whether this type of technical tool development truly serves patient interests. Patients are not modelling experts, nor perhaps even the primary users, and meaningful participation would likely require significant time, energy and effort and other resources that may already be strained, especially in the context of serious illness.

Still, patient perspectives can have an important role in challenging assumptions held by professionals and revealing mismatches between planned and actual care. While this input may not directly influence the modelling method itself, it can highlight situations where the language needs to remain flexible and responsive. This motivated also the effort to include patient interviews in this study. Therefore, while patient involvement should not be dismissed, future research should carefully consider when, how, and to what extent patients are involved in such development processes and how will they benefit from the result. Simply involving patients does not automatically equal meaningful inclusion.

5.3.4 The flexibility paradox in CJML modelling

Despite CJML being a newer language, its flexibility allowed for successful adaptation to modelling needs. It has also proven to be user-friendly even for individuals without prior modelling experience, with resulting models often aligning with correct modelling logic (Halvorsrud, Haugstveit, et al., 2016; Halvorsrud et al., 2023). However, the shortcomings identified in this study emerged particularly in more advanced use cases, where CJML was applied to increasingly complex examples. In these instances, the user-friendliness that benefits novice users began to work against effective modelling. Shortcomings, such as handling temporal complexity, suggest that improvements should focus not only on visual tools but especially on clearer and more structured guidelines.

As CJML is to serve as an accessible modelling language for a wide user base (Halvorsrud et al., 2023), it is essential to consider the trade-off between the simplicity of its guidance and the consistency of its application. While ease of use can promote broader adoption, overly open-ended guidelines may lead to variation in modelling quality and interpretation. Although such flexibility has been intentionally embedded in CJML's development to support user-friendliness, this study approaches the issue from a different angle. For experienced modellers, who are accustomed to stricter syntactic or semantic constraints, this openness can become a challenge rather than a benefit. Their familiarity with rule-based modelling may in fact amplify divergent modelling choices when working with a language that accommodates broad interpretation.

This potential for inconsistency may not pose issues during initial, exploratory use. However, it becomes increasingly problematic when automation or tooling is introduced. As observed in the beta version of the modelling tool, issues arise in how objects can be combined, how touchpoints align, and how the timeline behaves – modelling is not as flexible anymore. These challenges highlight the tension between user-friendly, flexible design and the need for formal structure when aiming for scalable or automated modelling applications.

If this openness is indeed an intentional feature, it should be made explicit to modellers and users. It is therefore worth reflecting on whether CJML guidelines should be made more prescriptive, or whether they should instead be explicitly framed as flexible modelling heuristics, with clear boundaries on acceptable adaptation.

5.4 Summary of discussion

Process modelling serves multiple purposes. In this study, the focus was first on managing variation by looking at typical, standardized patient pathways. Then, the importance of acknowledging variability was emphasised by treating the pathways as actual, individual patient journeys. Process modelling not only describes current practices but also acts as a tool for continuous improvement and learning in healthcare processes. PJDs and repeated failures in care highlight where deviations occur, and by knowing what was attempted and what should have happened, such disruptions can be anticipated and prevented in the future.

More broadly, this study highlights the need to evaluate all modelling languages in light of the unique, complex demands of healthcare (Vesinurm, 2025). No single modelling language currently addresses all of these dimensions comprehensively. For instance, UML has shown strength in assigning responsibility through use-case diagrams and structuring information systematically, making it suitable for visualising organisational roles and data relationships. BPMN, in turn, excels in representing organisational workflows, especially through its pools, swimlanes and message flows, making it well-suited for modelling communication across care units. CJML offers strong support for patient involvement, experience representation and co-creative care processes, although it still lacks in complex areas requiring high-level of detail.

Therefore, comparative analysis, linking specific modelling challenges to the strengths of each language, can provide the foundation for defining essential modelling requirements. These findings may be used to guide the refinement of existing languages or inform the development of hybrid approaches that selectively adopt useful features across languages. Ultimately, establishing a clear set of modelling requirements and corresponding strategies is critical for building modelling languages that can serve the practical, ethical and operational demands of future healthcare environments.

CJML is a useful way to model patient journeys, especially in making them patient-centred. Breaking the process into smaller parts can make the model easier to understand and use. While CJML was flexible and worked well for basic use, more complex cases revealed some limitations. The discussion also reflected on the basics, possibilities and constraints of patient process modelling. For instance, patients may not be the main users of the models, but their perspective can still bring valuable insights to development. However, careful thought is needed when increasing patient involvement and further developing CJML.

5.5 Strengths and limitations of the study

This study has several strengths and limitations that should be acknowledged.

One of the key strengths of this thesis lies in the opportunity to involve a wide range of relevant stakeholders throughout the research process. Each participant has had a meaningful and influential role in shaping the ultimate objectives this study relates to. Such comprehensive engagement is not self-evident in studies of this kind, where access to different perspectives can be limited. This not only adds to the relevance and credibility of the results but also provides a solid foundation for future research.

The study was able to draw on a broad and appropriate knowledge base, and further evaluation is mainly recommended from individuals with specific experience in patient pathway modelling. Once this has been done, the process logic and outcomes can be considered as reliable as possible: such that further validation would primarily be required in a real-life setting. The results of this study can therefore be refined to meet scientific standards with relatively limited additional effort, potentially even to a generalisable extent.

However, some limitations emerged along the research process, and they are outlined next below.

First, the data collection was based on a limited sample of HCPs involved in kidney cancer care. While participants provided valuable insights, the sample may not fully represent the diversity of roles, experiences or care settings across the broader kidney cancer treatment nature. Most notably, direct patient involvement was minimal. Although efforts were made to include patients, only one interview was conducted due to the sensitivity of the topic and scheduling difficulties.

However, the role of patients in this type of research may not always be necessary or even appropriate as shortly discussed in section 5.3.3. Even though the modelling method itself may not be relevant for patients, their perspective can help ensure the process reflects real experiences. This also raises a broader question of how much information is truly useful for patients, and when it might become unnecessary or even burdensome. As a result, the study has a limited ability to fully capture lived experiences, particularly psychosocial aspects and patient preferences.

Second, the selection of participating experts influenced the focus of the findings. As it became evident during the workshops, the Meilahti Cancer Centre in Helsinki primarily treats stage IV kidney cancer patients. Therefore, interviewees had detailed knowledge of late-stage care but lacked insight into earlier stages (I–III), limiting the generalisability of the models across the full disease continuum. This limitation was outside the researcher's control and only became apparent during data collection.

Third, the order of the workshops was not predetermined but based on hospital availability. As a result, earlier sessions shaped the researcher's approach to later ones. While this iterative process introduced some bias, it also enabled deeper questioning and helped clarify inconsistencies that later benefitted the model-building process and supported the study's aim to reflect both typical and actual patient journeys.

Fourth, the exclusive focus on kidney cancer limits the generalisability of findings to other chronic or complex healthcare conditions. Although many of the modelling challenges identified are common across care types, disease-specific factors like treatment cycles and differing patient needs may affect how the findings apply elsewhere.

Additionally, this study concentrated on post-diagnostic care processes and did not address risk assessment or primary prevention. Although preventive care and long-term healthy behaviours are critical for sustainable healthcare systems, especially in reducing incidence and improving access, they were beyond the scope of this research. In practice, diagnoses will continue to occur despite preventative efforts, underlining the importance of ensuring that once a diagnosis is made, the patient's care pathway is smooth, efficient and well-supported - both to improve health outcomes and to manage costs effectively. Therefore, this study contributes most directly to the post-detection phases rather than disease prevention.

6 Conclusions

This study explored the modelling of a typical kidney cancer patient journey through a patient-centred lens, emphasising the complex, multi-producer nature of cancer care and the often-limited role of patients in decision-making. By dividing the care pathway into five key stages, detection, diagnosis, treatment, post-treatment survivorship and end-of-life care, the research highlighted the need for improved transparency, support for decision-making, modularity and communication across the continuum of care.

Conducted through a Design Science Research (DSR) approach, the study followed an iterative process of modelling, evaluation and refinement, engaging domain experts to assess the feasibility and relevance of the proposed modelling solutions. A comparative evaluation of Unified Modelling Language (UML), Business Process Model and Notation (BPMN) and Customer Journey Modelling Language (CJML) revealed differing capabilities in representing decision points, information flow and patient involvement. While UML and BPMN offer formal structures for process visualisation and optimisation, they fall short in supporting patient-centred aspects. CJML as a customer-centred modelling language was found promising in addressing these gaps.

Through iterative development and feedback, this research proposed developments to CJML. Improvements such as modularity, more diverse divers action cases, clearer decision representation and improved visual tools are proposed to improve the usability of CJML and its capacity to support automation, care coordination and patient empowerment.

While the workshop provided strong support for the proposed improvements, future research is needed to assess their usability and effectiveness across a broader modelling audience, including both novice and experienced users. In particular, practical testing of developments, such as more precise specifications for sub-processes, looping events and decision-making, will be essential to determine their impact on model quality, consistency and applicability in real-world healthcare settings.

In general, future research should further evaluate CJML's potential through real-world implementation in clinical settings and consider whether involving patients directly would enhance its usability and comprehension. Additionally, more systematic integration with healthcare information systems and decision-support tools could be explored to validate CJML's scalability and automation potential. Finally, longitudinal studies are needed to assess how patient-centred modelling and co-creation of health impacts care outcomes, communication practices and shared decision-making in diverse care contexts. Further attention should also be given to the role of patients in process models: are they expected to be active participants, beneficiaries or simply, informed parties? Understanding this will help clarify the boundaries of meaningful involvement and guide the development of tools that genuinely support patient-centred care.

Ultimately, the study contributes to more inclusive, understandable and adaptable modelling practices in healthcare. It supports the evolution of CJML towards a modelling language capable of meeting the nuanced demands of patient-centred care. within complex healthcare environments.

References

Ahn, S., Smith, M. L., Altpeter, M., Post, L., & Ory, M. G. (2015). Healthcare cost savings estimator tool for chronic disease self-management program: a new tool for program administrators and decision makers. *Front Public Health*, *3*, 42. https://doi.org/10.3389/fpubh.2015.00042

Andellini, M., Riesgo, S. F., Morolli, F., Ritrovato, M., Cosoli, P., Petruzzellis, S., & Rosso, N. (2017). Experimental application of Business Process Management technology to manage clinical pathways: a pediatric kidney transplantation follow up case. *Bmc Medical Informatics and Decision Making*, *17*. https://doi.org/10.1186/s12911-017-0546-x

Anhang Price, R., Zapka, J., Edwards, H., & Taplin, S. H. (2010). Organizational factors and the cancer screening process. *J Natl Cancer Inst Monogr*, *2010*(40), 38-57. https://doi.org/10.1093/jncimonographs/lgq008

Ardito, C., Caivano, D., Colizzi, L., Dimauro, G., & Verardi, L. (2020). Design and Execution of Integrated Clinical Pathway: A Simplified Meta-Model and Associated Methodology. *Information*, *11*(7). https://doi.org/10.3390/info11070362

Arem, H., Moses, J., Cisneros, C., Blondeau, B., Nekhlyudov, L., Killackey, M., & Pratt-Chapman, M. L. (2022). Cancer Provider and Survivor Experiences With Telehealth During the COVID-19 Pandemic. *JCO Oncol Pract*, *18*(4), e452-e461. https://doi.org/10.1200/OP.21.00401

Ash, J. S., Berg, M., & Coiera, E. (2004). Some unintended consequences of information technology in health care: the nature of patient care information system-related errors. *Journal of the American Medical Informatics Association*, *11*(2), 104-112. https://doi.org/10.1197/jamia.M1471

Askari, M., Tam, J. L. Y. Y., & Klundert, J. (2021). The effectiveness of clinical pathway software in inpatient settings: A systematic review. *International Journal of Medical Informatics*, *147*. https://doi.org/10.1016/j.ijmedinf.2020.104374

Askari, M., Westerhof, R., Eslami, S., Medlock, S., de Rooij, S. E., & Abu-Hanna, A. (2013). A combined disease management and process modeling approach for assessing and improving care processes: a fall management case-study. *Int J Med Inform*, *82*(10), 1022-1033. https://doi.org/10.1016/j.ijmedinf.2013.06.011

Aspland, E., Gartner, D., & Harper, P. (2019). Clinical pathway modelling: a literature review. *Health Syst (Basingstoke)*, *10*(1), 1-23. https://doi.org/10.1080/20476965.2019.1652547

Barbagallo, S., Corradi, L., de Ville de Goyet, J., Iannucci, M., Porro, I., Rosso, N., Tanfani, E., & Testi, A. (2015). Optimization and planning of operating theatre activities: an original definition of pathways and process modeling. *BMC Med Inform Decis Mak*, *15*, 38. https://doi.org/10.1186/s12911-015-0161-7

Barth, J. H., Misra, S., Aakre, K. M., Langlois, M. R., Watine, J., Twomey, P. J., & Oosterhuis, W. P. (2016). Why are clinical practice guidelines not followed? *Clin Chem Lab Med*, *54*(7), 1133-1139. https://doi.org/10.1515/cclm-2015-0871

Bhatt, B., & Nandu, M. (2021). An Overview of Structural UML Diagrams. *International Research Journal of Engineering and Technlogy (IRJET)*, *08*(08).

Bitner, M. J., Ostrom, A. L., & Morgan, F. N. (2008). Service blueprinting: a practical technique for service innovation. *California management review*, *50*(3), 66-94. https://doi.org/https://doi.org/10.2307/41166446

Blomkvist, J., Holmlid, S., & Segelström, F. (2010). Service design research: yesterday, today and tomorrow. In M. Stickdorn, & Schneider, J. (Ed.), *This is service design thinking: basics-tools-cases* (pp. 308-315).

Bogale, B., Solem, I. K. L., Celius, E. G., & Halvorsrud, R. (2024). *Visual Modeling of Multiple Sclerosis Patient Pathways: The Healthcare Workers' Perspectives* Nordic Conference on Digital Health and Wireless Solutions,

Bogale, B., Vesinurm, M., Lillrank, P., Celius, E. G., & Halvorsrud, R. (2024). Visual Modeling Languages in Patient Pathways: Scoping Review. *Interact J Med Res*, *13*, e55865. https://doi.org/10.2196/55865

Burwitz, M., Schlieter, H., & Esswein, W. (2013). Modeling clinical pathways-design and application of a domain-specific modeling language. *Wirtschaftsinformatik Proceedings 2013*, *83*.

Campbell, H., Hotchkiss, R., Bradshaw, N., & Porteous, M. (1998). Integrated care pathways. *BMJ*, *316*(7125), 133-137. https://doi.org/10.1136/bmj.316.7125.133

Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff (Millwood)*, *32*(2), 223-231. https://doi.org/10.1377/hlthaff.2012.1133

Cassidy, S., Solvang, Ø. S., Lintvedt, O. K., Solvoll, T., & Granja, C. (2022). Assessing Methods to Model Patient-Centric Care Pathways across Multiple Healthcare Systems. Proceedings from The Fourteenth International Conference on eHealth, Telemedicine, and Social Medicine, Porto, Portugal.

Chan, R. J., Crichton, M., Crawford-Williams, F., Agbejule, O. A., Yu, K., Hart, N. H., de Abreu Alves, F., Ashbury, F. D., Eng, L., Fitch, M., Jain, H., Jefford, M., Klemanski, D., Koczwara, B., Loh, K., Prasad, M., Rugo, H., Soto-Perez-de-Celis, E., van den Hurk, C.,...Multinational Association of Supportive Care in Cancer Survivorship Study, G. (2021). The efficacy, challenges, and facilitators of telemedicine in post-treatment cancer survivorship care: an overview of systematic reviews. *Ann Oncol*, *32*(12), 1552-1570. https://doi.org/10.1016/j.annonc.2021.09.001

Cheung, M. C., Earle, C. C., Rangrej, J., Ho, T. H., Liu, N., Barbera, L., Saskin, R., Porter, J., Seung, S. J., & Mittmann, N. (2015). Impact of aggressive management and palliative care on cancer costs in the final month of life. *Cancer*, *121*(18), 3307-3315. https://doi.org/10.1002/cncr.29485

Chu, S., & Cesnik, B. (1998). Improving clinical pathway design: lessons learned from a computerised prototype. *Int J Med Inform*, *51*(1), 1-11. https://doi.org/10.1016/s1386-5056(98)00003-3

Combi, C., Oliboni, B., Zardini, A., & Zerbato, F. (2017). A Methodological Framework for the Integrated Design of Decision-Intensive Care Pathways-an Application to the Management of COPD Patients. *J Healthc Inform Res*, *1*(2), 157-217. https://doi.org/10.1007/s41666-017-0007-4

Curry, S. J. (2000). Organizational interventions to encourage guideline implementation. *Chest*, *118*(2 Suppl), 40S-46S. https://doi.org/10.1378/chest.118.2_suppl.40s

Danaher, T. S., Danaher, P. J., Sweeney, J. C., & McColl-Kennedy, J. R. (2024). Dynamic Customer Value Cocreation in Healthcare. *Journal of Service Research*, *27*(2), 177-193. https://doi.org/10.1177/10946705231161758

Debela, D. T., Muzazu, S. G., Heraro, K. D., Ndalama, M. T., Mesele, B. W., Haile, D. C., Kitui, S. K., & Manyazewal, T. (2021). New approaches and procedures for cancer treatment: Current perspectives. *SAGE Open Med*, *9*, 20503121211034366. https://doi.org/10.1177/20503121211034366

Di Ciccio, C., Marrella, A., & Russo, A. (2015). Knowledge-Intensive Processes: Characteristics, Requirements and Analysis of Contemporary Approaches. *Journal on Data Semantics*, *4*(1), 29-57. https://doi.org/10.1007/s13740-014-0038-4

Dong, P., & Gewirtz, D. A. (2022). Editorial: Risks and Benefits of Adjuvants to Cancer Therapies. *Front Oncol*, *12*, 913626. https://doi.org/10.3389/fonc.2022.913626

Dorri, S., Asadi, F., Olfatbakhsh, A., & Kazemi, A. (2020). A Systematic Review of Electronic Health (eHealth) interventions to improve physical activity in patients with breast cancer. *Breast Cancer*, *27*(1), 25-46. https://doi.org/10.1007/s12282-019-00982-3

Earle, C. C., Park, E. R., Lai, B., Weeks, J. C., Ayanian, J. Z., & Block, S. (2003). Identifying potential indicators of the quality of end-of-life cancer care from administrative data. *J Clin Oncol*, *21*(6), 1133-1138. https://doi.org/10.1200/JCO.2003.03.059

Eklund, A., Vesinurm, M., & Torkki, P. (2024). Explorative study on the utilization of patient pathways in Finnish public healthcare.

Eriksson, H.-E., Penker, M., & Object Management, G. (2000). *Business modeling with UML : business patterns at work*. John Wiley & Sons, Inc. http://www.loc.gov/catdir/toc/onix04/99058911.html

Ferrante, S., Bonacina, S., Pozzi, G., Pinciroli, F., & Marceglia, S. (2016). A Design Methodology for Medical Processes. *Appl Clin Inform*, *7*(1), 191-210. https://doi.org/10.4338/ACI-2015-08-RA-0111

Følstad, A., & Kvale, K. (2018). Customer journeys: a systematic literature review. *Journal of Service Theory and Practice*, *28*(2), 196-227.

Fossa, S. D., Kjolseth, I., & Lund, G. (1982). Radiotherapy of metastases from renal cancer. *Eur Urol*, *8*(6), 340-342. https://doi.org/10.1159/000473553

Gallan, A. S., Jarvis, C. B., Brown, S. W., & Bitner, M. J. (2013). Customer positivity and participation in services: an empirical test in a health care context. *Journal of the academy of marketing science*, *41*, 338-356. https://doi.org/10.1007/s11747-012-0307-4

Gustafsson, A., & Johnson, M. D. (2003). *Competing in a service economy : how to create a competitive advantage through service development and innovation* (1st ed.). Jossey-Bass.

Haltia, O., Vesinurm, M., Leskela, R. L., Rahko, E., Tyynela-Korhonen, K., Lehto, J. T., Saarto, T., & Akren, O. M. (2023). The effect of palliative outpatient units on resource use for cancer patients in Finland. *Acta Oncol*, *62*(9), 1118-1123. https://doi.org/10.1080/0284186X.2023.2241988

Halvorsrud, R., Haugstveit, I. M., & Pultier, A. (2016). *Evaluation of a modelling language for customer journeys* 2016 IEEE Symposium on Visual Languages and Human-Centric Computing (VL/HCC), Cambridge, UK.

Halvorsrud, R., Kvale, K., & Følstad, A. (2016). Improving service quality through customer journey analysis. *Journal of Service Theory and Practice*, *26*(6), 840-867. https://doi.org/10.1108/jstp-05-2015-0111

Halvorsrud, R., Lee, E., Haugstveit, I. M., & Følstad, A. (2014, 9-11 April). *Components of a Visual Language for Service Design* ServDes. 2014 Service Future, Proceedings of the fourth Service Design and Service Innovation Conference, Lancaster University, United Kingdom.

Halvorsrud, R., Lillegaard, A. L., Røhne, M., & Jensen, A. M. (2018). Managing complex patient journeys in healthcare. *In Pfannstiel, M.A. and Rasche, C. (Eds.)* (Service Design and Service Thinking in Healthcare and Hospital Management), 329-346. (Springer)

Halvorsrud, R., Røhne, M., Celius, E. G., Moen, S. M., & Strisland, F. (2019, 12 -13 Nov 2019). Application of Patient Journey Methodology to Explore Needs for Digital Support. 17th Scandinavian Conference on Health Informatics,

Halvorsrud, R., Sanchez, O. R., Boletsis, C., & Skjuve, M. (2023). Involving users in the development of a modeling language for customer journeys. *Software and Systems Modeling*, *22*(5), 1589–1618. https://doi.org/10.1007/s10270-023-01081-w

Haywood, K., Marshall, S., & Fitzpatrick, R. (2006). Patient participation in the consultation process: a structured review of intervention strategies. *Patient Educ Couns*, *63*(1-2), 12-23. https://doi.org/10.1016/j.pec.2005.10.005

Healthcare Financial Management, A. (2003). Achieving operating room efficiency through process integration. *Healthc Financ Manage*, *57*(3), suppl 1-7 following 112. https://www.ncbi.nlm.nih.gov/pubmed/12793445

Henson, L. A., Gao, W., Higginson, I. J., Smith, M., Davies, J. M., Ellis-Smith, C., & Daveson, B. A. (2015). Emergency department attendance by patients with cancer in their last month of life: a systematic review and meta-analysis. *J Clin Oncol*, *33*(4), 370-376. https://doi.org/10.1200/JCO.2014.57.3568

Hevner, A. R., March, S. T., Park, J., & Ram, S. (2004). Design science in information systems research. *MIS quarterly*, *28*(1), 75-105. https://doi.org/https://doi.org/10.2307/25148625

Hiatt, R. A., & Rimer, B. K. (1999). A new strategy for cancer control research. *Cancer Epidemiology Biomarkers & Prevention*, *8*(11), 957-964.

Hugar, L. A., Wulff-Burchfield, E. M., Winzelberg, G. S., Jacobs, B. L., & Davies, B. J. (2021). Incorporating palliative care principles to improve patient care and quality of life in urologic oncology. *Nat Rev Urol*, *18*(10), 623-635. https://doi.org/10.1038/s41585-021-00491-z

Hunt, J. (2003). *Guide to the unified process featuring UML, Java, and design patterns*. Springer.

HUS. (2025a). *Care pathway for renal cancer*. Retrieved February 12, 2025 from https://www.hus.fi/en/patient/treatments-and-examinations/cancer/care-pathway-renal-cancer#if-the-disease-recurs-or-treat

HUS. (2025b). *Syöpäkeskus*. https://www.hus.fi/potilaalle/sairaalat-ja-toimipisteet/syopakeskus

HUS. (2025c). *Tietoa meistä*. Retrieved May 5, 2025 from https://www.hus.fi/tietoa-meista

Iivari, J. (2007). A paradigmatic analysis of information systems as a design science. *Scandinavian journal of information systems*, *19*(2), Article 5.

Jayson, M., & Sanders, H. (1998). Increased incidence of serendipitously discovered renal cell carcinoma. *Urology*, *51*(2), 203-205. https://doi.org/10.1016/s0090-4295(97)00506-2

Jewett, P. I., Vogel, R. I., Ghebre, R., Hui, J. Y. C., Parsons, H. M., Rao, A., Sagaram, S., & Blaes, A. H. (2022). Telehealth in cancer care during COVID-19: disparities by age, race/ethnicity, and residential status. *J Cancer Surviv*, *16*(1), 44-51. https://doi.org/10.1007/s11764-021-01133-4

Ju, F., Lee, H. K., Yu, X., Faris, N. R., Rugless, F., Jiang, S., Li, J., & Osarogiagbon, R. U. (2017). Reducing Bottlenecks to Improve the Efficiency of the Lung Cancer Care Delivery Process: A Process Engineering Modeling Approach to Patient-Centered Care. *J Med Syst*, *42*(1), 16. https://doi.org/10.1007/s10916-017-0873-6

Kaikki syövästä. (2025a). *Hormonihoidot*. Syöpäjärjestöt. Retrieved January 10, 2025 from https://kaikkisyovasta.fi/tietoa-syovasta/syopahoidot/hormonihoidot/

Kaikki syövästä. (2025b). *Immunologiset hoidot*. Syöpäjärjestöt. Retrieved January 10, 2025 from https://kaikkisyovasta.fi/tietoa-syovasta/syopahoidot/immunologiset-hoidot/

Kaikki syövästä. (2025c). *Munuaissyöpä*. Syöpäjärjestöt. Retrieved February 11, 2025 from https://kaikkisyovasta.fi/tietoa-syovasta/syopataudit/munuaissyopa-2/

Kaikki syövästä. (2025d). *Sädehoito*. Syöpäjärjestöt. Retrieved Janurary 10, 2025 from https://kaikkisyovasta.fi/tietoa-syovasta/syopahoidot/sadehoito/

Kaikki syövästä. (2025e). *Solunsalpaajat eli sytostaatit*. Syöpäjärjestöt. Retrieved Janurary 10, 2025 from https://kaikkisyovasta.fi/tietoa-syovasta/syopahoidot/solunsalpaajat-eli-sytostaatit/

Kaikki syövästä. (2025f). *Syöpähoidot*. Syöpäjärjestöt. Retrieved January 10, 2025 from https://kaikkisyovasta.fi/tietoa-syovasta/syopahoidot/

Kaikki syövästä. (2025g). *Syövän leikkaus*. Syöpäjärjestöt. Retrieved Janurary 10, 2025 from https://kaikkisyovasta.fi/tietoa-syovasta/syopahoidot/syovan-leikkaus/

Kaikki syövästä. (2025h). *Täsmälääkkeet eli biologiset syöpälääkkeet*. Syöpäjärjestöt. Retrieved January 10, 2025 from https://kaikkisyovasta.fi/tietoa-syovasta/syopahoidot/tasmalaakkeet-eli-biologiset-syopalaakkeet/

Kaipio, J., Laaveri, T., Hypponen, H., Vainiomaki, S., Reponen, J., Kushniruk, A., Borycki, E., & Vanska, J. (2017). Usability problems do not heal by themselves: National survey on physicians' experiences with EHRs in Finland. *Int J Med Inform*, *97*, 266-281. https://doi.org/10.1016/j.ijmedinf.2016.10.010

Keskimäki, I., Tynkkynen, L. K., Reissell, E., Koivusalo, M., Syrjä, V., Vuorenkoski, L., Rechel, B., & Karanikolos, M. (2023). Finland: Health system review 2019. *Health Systems in Transition*, *21*(2), 1-166.

Kumarapeli, P., De Lusignan, S., Ellis, T., & Jones, B. (2007). Using Unified Modelling Language (UML) as a process-modelling technique for clinical-research process improvement. *Medical Informatics and the Internet in Medicine*, *32*(1), 51-64. https://doi.org/10.1080/14639230601097705

Larsen, A. G., Halvorsrud, R., Berg, R. E., & Vesinurm, M. (2024). *Dual perspective modeling of patient pathways: a case study on kidney cancer* Nordic Conference on Digital Health and Wireless Solutions,

Laukka, E., Tuunanen, T., Jansson, M., Vanhanen, M., Hirvonen, N., Palukka, J., Vesinurm, M., & Torkki, P. (2025). Value Cocreation and Codestruction in Digital Health Services: Protocol for a Systematic Review. *JMIR Res Protoc*, *14*, e63015. https://doi.org/10.2196/63015

Lenz, R., & Reichert, M. (2007). IT support for healthcare processes–premises, challenges, perspectives. *Data & Knowledge Engineering*, *61*(1), 39-58.

Lillrank, P. (2018). The Logics of Healthcare: The Professional’s Guide to Health Systems Science. *Taylor & Francis*.

Lillrank, P., & Liukko, M. (2004). Standard, routine and non-routine processes in health care. *Int J Health Care Qual Assur Inc Leadersh Health Serv*, *17*(1), 39-46. https://doi.org/10.1108/09526860410515927

Lu, R., & Sadiq, S. (2007, April 25-27, 2007). *A Survey of Comparative Business Process Modeling Approaches* BIS 2007, Poznan, Poland.

Lyratzopoulos, G., Abel, G. A., McPhail, S., Neal, R. D., & Rubin, G. P. (2013). Gender inequalities in the promptness of diagnosis of bladder and renal cancer after symptomatic presentation: evidence from secondary analysis of an English primary care audit survey. *BMJ Open*, *3*(6). https://doi.org/10.1136/bmjopen-2013-002861

Manchaiah, V. K., Stephens, D., & Meredith, R. (2011). The patient journey of adults with hearing impairment: the patients' views. *Clin Otolaryngol*, *36*(3), 227-234. https://doi.org/10.1111/j.1749-4486.2011.02320.x

Mattila, K., Peltola, K., & Jaakkola, P. (2022). Edenneen munuaissyövän hoito. *Duodecim*, *138*(17), 1525-1533.

Moch, H., Cubilla, A. L., Humphrey, P. A., Reuter, V. E., & Ulbright, T. M. (2016). The 2016 WHO Classification of Tumours of the Urinary System and Male Genital Organs-Part A: Renal, Penile, and Testicular Tumours. *Eur Urol*, *70*(1), 93-105. https://doi.org/10.1016/j.eururo.2016.02.029

Mould, G., Bowers, J., & Ghattas, M. (2010). The evolution of the pathway and its role in improving patient care. *Qual Saf Health Care*, *19*(5), e14. https://doi.org/10.1136/qshc.2009.032961

Murphy, D. R., Laxmisan, A., Reis, B. A., Thomas, E. J., Esquivel, A., Forjuoh, S. N., Parikh, R., Khan, M. M., & Singh, H. (2014). Electronic health record-based triggers to detect potential delays in cancer diagnosis. *BMJ Qual Saf*, *23*(1), 8-16. https://doi.org/10.1136/bmjqs-2013-001874

Oben, P. (2020). Understanding the Patient Experience: A Conceptual Framework. *J Patient Exp*, *7*(6), 906-910. https://doi.org/10.1177/2374373520951672

Object Management Group (OMG). (2013). Business Process Model and Notation (BPMN) Version 2.0.2. In: Object Management Group.

Object Management Group (OMG). (2017). OMG Unified Modeling Language (OMG UML), Superstructure, Version 2.5.1. In: Object Management Group.

Object Management Group (OMG). (2024). Decision Model and Notation (DMN) Version 1.6 beta 1. In: Object Management Group.

Olsson, L. E., Hansson, E., Ekman, I., & Karlsson, J. (2009). A cost-effectiveness study of a patient-centred integrated care pathway. *J Adv Nurs*, *65*(8), 1626-1635. https://doi.org/10.1111/j.1365-2648.2009.05017.x

Pahl, C., Supriyanto, E., & Detschew, V. (2015). Evaluation of UML Modeling Tools for Clinical Pathways used in Health Information Systems. *2015*

10th Iberian Conference on Information Systems and Technologies (Cisti).
Panella, M., Marchisio, S., & Di Stanislao, F. (2003). Reducing clinical variations with clinical pathways: do pathways work? *Int J Qual Health Care*, *15*(6), 509-521. https://doi.org/10.1093/intqhc/mzg057
Patrício, L., Sangiorgi, D., Mahr, D., Caic, M., Kalantari, S., & Sundar, S. (2020). Leveraging service design for healthcare transformation: toward people-centered, integrated, and technology-enabled healthcare systems. *Journal of Service Management*, *31*(5), 889-909. https://doi.org/10.1108/Josm-11-2019-0332
Peffers, K., Tuunanen, T., Rothenberger, M. A., & Chatterjee, S. (2007). A Design Science Research Methodology for Information Systems Research. *Journal of Management Information Systems*, *24*(3), 45-77. https://doi.org/10.2753/MIS0742-1222240302
Plsek, P. E., & Greenhalgh, T. (2001). Complexity science: The challenge of complexity in health care. *BMJ*, *323*(7313), 625-628. https://doi.org/10.1136/bmj.323.7313.625
Pufahl, L., Zerbato, F., Weber, B., & Weber, I. (2022). BPMN in healthcare: Challenges and best practices. *Information Systems*, *107*.
Recker, J., Zur Muehlen, M., Siau, K., Erickson, J., & Indulska, M. (2009). Measuring method complexity: UML versus BPMN. *Proceedings of the fifteenth Americas conference on information systems*, 1-9. (Association for Information Systems.)
Reis, Z. S. N., Maia, T. A., Marcolino, M. S., Becerra-Posada, F., Novillo-Ortiz, D., & Ribeiro, A. L. P. (2017). Is There Evidence of Cost Benefits of Electronic Medical Records, Standards, or Interoperability in Hospital Information Systems? Overview of Systematic Reviews. *JMIR Med Inform*, *5*(3), e26. https://doi.org/10.2196/medinform.7400
Resnicow, K., & Page, S. E. (2008). Embracing chaos and complexity: a quantum change for public health. *Am J Public Health*, *98*(8), 1382-1389. https://doi.org/10.2105/AJPH.2007.129460
Scelo, G., & Larose, T. L. (2018). Epidemiology and Risk Factors for Kidney Cancer. *J Clin Oncol*, *36*(36), JCO2018791905. https://doi.org/10.1200/JCO.2018.79.1905
Scelo, G., Li, P., Chanudet, E., & Muller, D. C. (2018). Variability of Sex Disparities in Cancer Incidence over 30 Years: The Striking Case of Kidney Cancer. *Eur Urol Focus*, *4*(4), 586-590. https://doi.org/10.1016/j.euf.2017.01.006
Scheuerlein, H., Rauchfuss, F., Dittmar, Y., Molle, R., Lehmann, T., Pienkos, N., & Settmacher, U. (2012). New methods for clinical pathways-Business Process Modeling Notation (BPMN) and Tangible Business Process Modeling (t.BPM). *Langenbecks Arch Surg*, *397*(5), 755-761. https://doi.org/10.1007/s00423-012-0914-z
Schrijvers, G., van Hoorn, A., & Huiskes, N. (2012). The care pathway: concepts and theories: an introduction. *Int J Integr Care*, *12*(Spec Ed Integrated Care Pathways), e192. https://doi.org/10.5334/ijic.812

Seys, D., Panella, M., VanZelm, R., Sermeus, W., Aeyels, D., Bruyneel, L., Coeckelberghs, E., & Vanhaecht, K. (2019). Care pathways are complex interventions in complex systems: New European Pathway Association framework. *International Journal of Care Coordination*, *22*(1), 5-9. https://doi.org/10.1177/2053434519839195

Shiki, N., Ohno, Y., Fujii, A., Murata, T., & Matsumura, Y. (2008). Unified Modeling Language (UML) for hospital-based cancer registration processes. *Asian Pac J Cancer Prev*, *9*(4), 789-796. https://www.ncbi.nlm.nih.gov/pubmed/19256778

Soman, D. A., Koscelny, S. N., Neyens, D., Dietrich, A., Narasimhan, M., Taaffe, K., Allison, D., Group, R. P. S., & Joseph, A. (2025). Using patient journey mapping and provider workflows to understand process barriers to pediatric mental and behavioral health care in emergency departments. *Appl Ergon*, *126*, 104512. https://doi.org/10.1016/j.apergo.2025.104512

Sonnenberg, C., & Vom Brocke, J. (2012, May 14-15, 2012). *Evaluations in the science of the artificial – Reconsidering the build-evaluate pattern in design science research* Advances in Theory and Practice: 7th International Conference, DESRIST 2012, Las Vegas, NV, USA.

Stickdorn, M., & Schneider, J. (2011). *This is service design thinking : basics-tools-cases* (Paperback edition. ed.). BIS Publishers.

Swami, U., Nussenzveig, R. H., Haaland, B., & Agarwal, N. (2019). Revisiting AJCC TNM staging for renal cell carcinoma: quest for improvement. *Ann Transl Med*, *7*(Suppl 1), S18. https://doi.org/10.21037/atm.2019.01.50

Taplin, S. H., Anhang Price, R., Edwards, H. M., Foster, M. K., Breslau, E. S., Chollette, V., Prabhu Das, I., Clauser, S. B., Fennell, M. L., & Zapka, J. (2012). Introduction: Understanding and influencing multilevel factors across the cancer care continuum. *J Natl Cancer Inst Monogr*, *2012*(44), 2-10. https://doi.org/10.1093/jncimonographs/lgs008

Taplin, S. H., & Rodgers, A. B. (2010). Toward improving the quality of cancer care: addressing the interfaces of primary and oncology-related subspecialty care. *J Natl Cancer Inst Monogr*, *2010*(40), 3-10. https://doi.org/10.1093/jncimonographs/lgq006

Tehrani, J., Liu, K., & Michell, V. (2013). *Semiotics-oriented method for generation of clinical pathways* LISS 2012: Proceedings of 2nd International Conference on Logistics, Informatics and Service Science,

THL. (2024). *Mitä on palliatiivinen hoito*. Terveyden ja hyvinvoinnin laitos. Retrieved January 10, 2025 from https://thl.fi/aiheet/ikaantyminen/elaman-loppuvaiheen-hoito/mita-on-palliatiivinen-hoito

Turajlic, S., Swanton, C., & Boshoff, C. (2018). Kidney cancer: The next decade. *J Exp Med*, *215*(10), 2477-2479. https://doi.org/10.1084/jem.20181617

Valentijn, P. P., Schepman, S. M., Opheij, W., & Bruijnzeels, M. A. (2013). Understanding integrated care: a comprehensive conceptual

framework based on the integrative functions of primary care. *Int J Integr Care*, *13*, e010. https://doi.org/10.5334/ijic.886
Vanhaecht, K., De Witte, K., Panella, M., & Sermeus, W. (2009). Do pathways lead to better organized care processes? *J Eval Clin Pract*, *15*(5), 782-788. https://doi.org/10.1111/j.1365-2753.2008.01068.x
Vehkamaki, A., Vesinurm, M., Helminen, R. R., Halminen, O., & Lillrank, P. (2024). Causes of care discontinuity in chronic outpatient care: A mixed method case study. *Health Serv Manage Res*, 9514848241307183. https://doi.org/10.1177/09514848241307183
Vesinurm, M. (2025). Managing Complex Patient Journeys: A Healthcare Operations Management Perspective. http://urn.fi/URN:ISBN:978-952-64-2366-1 (Aalto University)
Vesinurm, M., Dunweber, C., Rimestad, J., Landtblom, A. M., & Jennum, P. J. (2024). Patient experiences of narcolepsy and idiopathic hypersomnia in the Nordics: a patient journey map. *J Sleep Res*, e14376. https://doi.org/10.1111/jsr.14376
Vesinurm, M., Sylgren, I., Bengts, A., Torkki, P., & Lillrank, P. (2024). Concept analysis of patient journey disruptions : the obstacle of integrated care. *Journal of Integrated Care*, *32*(5), 37-58. https://doi.org/10.1108/JICA-08-2023-0060
Wallen, E. M., Pruthi, R. S., Joyce, G. F., & Wise, M. (2007). Kidney cancer. In *Urologic Diseases in America Project* (Vol. 177(6), pp. 337-368).
WHO. (2024). Setting the stage for the Telehealth quality of care tool. In *Telehealth quality of care tool*. Copenhagen: WHO Regional Office for Europe.
World Health Assembly. (2016). *Framework on integrated, people-centred health services*.
Yildiz, F., & Oksuzoglu, B. (2020). Teleoncology or telemedicine for oncology patients during the COVID-19 pandemic: the new normal for breast cancer survivors? *Future Oncol*, *16*(28), 2191-2195. https://doi.org/10.2217/fon-2020-0714
Zapka, J. G., Taplin, S. H., Solberg, L. I., & Manos, M. M. (2003). A framework for improving the quality of cancer care: The case of breast and cervical cancer screening. *Cancer Epidemiology Biomarkers & Prevention*, *12*(1), 4-13.
Zerbato, F., Oliboni, B., Combi, C., Campos, M., & Juarez, J. M. (2015). BPMN-based Representation and Comparison of Clinical Pathways for Catheter-related Bloodstream Infections. *2015 Ieee International Conference on Healthcare Informatics (Ichi 2015)*, 346-355. https://doi.org/10.1109/Ichi.2015.49

7 Appendixes

A. Healthcare professional workshop, question template

1. When the diagnosis is clear enough, how do you start building a treatment plan?
2. What do you think about treatment plans?
3. Does the treatment plan describe for an individual patient which is currently the most likely prognosis? Would it be useful?
4. To what extent is the treatment plan available and/or visible to patients? Should it be?
5. How do you communicate with other specialists involved in the patient's care (between different healthcare providers)? Does the treatment plan play a role in that? Should it play?
6. How do you monitor the patient's treatment process? Is the monitoring somehow documented?
7. What do you think about patients' self-reported data (PROM, PREM)? How important would it be to have such metrics?

B. Patient interview, template (in finnish)

Tämän tutkimuksen tarkoitus on kehittää visuaalinen monikerroksinen kuvauskieli kompleksisten potilaspolkujen kuvaamista, analyysia ja ohjausta varten. Tämä on tutkimus, jossa yritetään ymmärtää, miten krooinsta sairausta sairastavien potilaiden hoitopolkua ja prosesseja voitaisiin parantaa tiedonkulkuun ja kommunikaatioon liittyen.

Haastatellaan potilasta ja omaista yhdessä, jos potilas näin toivoo, mutta erikseenkin sopii.Potilaita haastatellaan kahdesti niin, että haastattelujen välissä heitä pyydetään pitämään päiväkirjaa kokemuksistaa terveydenhuoltojärjestelmän kanssa.

Tämän haastattelun tuloksia hyödynnetään Aalto-yliopiston, Oslon yliopiston ja SINTEF Digitalin Pathway-hankkeen kehitystyössä ja M. Vesinurmen väitöskirjatutkimuksessa. Vastaathan kysymyksiin oman kokemuksesi näkökulmasta.

Tausta

1. Taustakysymykset
   a) Ikä
   b) Sukupuoli
   c) Omaisen suhde potilaaseen (ja kesto)
   d) Kotikunta
   e) Elämäntilanne

f) Työtilanne
g) Toimintakyky
h) Sairauden vaihe
i) Miten kauan olet sairastanut tautia?
j) Taudin rajoitteet normaaliin elämään

2. Kerro tilanteestasi. Sinulla on diagnoosi.
a) Miten kaikki alkoi
b) Miten se vaikuttaa elämääsi

Potilaspolun kuvaus

Potilaspolun kaavoittaminen prosessivuokaavioiden avulla. Toteutetaan hyödyntäen ammattilaisten haastatteluiden perusteella ja Käypä hoito -suosituksien perusteella koottua prosessikaaviota MS-taudin tai munuaissyövän hoidosta.

Toteutetaan workshop tyylisesti. Esitellään uimaradat ja täytetään sitä mukaa, kun haastateltava kuvailee potilaspolkuaan.

3. Ketkä kaikki ovat hoitaneet sinua sairauteesi liittyen? Mitä nämä kontaktit ovat sisältäneet? Kootaan post-it lapuilla tai tietokoneella.
a) Onko sinulla kontaktihenkilöä, johon olla yhteydessä tautiisi liittyen?

Potilaspolun ongelmakohdat

4. Onko sinulle tapahtunut taudin suhteen jotain ikävää, hämmentävää tai muuta negatiivista? (Esimerkiksi, ettet ole saanut tietoa jostain asiasta, epäselviä ohjeita, jätetty yksin ei kuunneltu) Kerro esimerkkejä.
a) Miten reagoit? Mitä teit?
b) Kuka teki mitä?
c) Mitä odotit tapahtuvat, mitä ei tapahtunut?
d) Miltä sinusta tuntui?
e) Mitä tästä seurasi?
f) Mistä tämä johtui? Onko sinulla ajatusta, mistä tämä johtui?

5. Kuvaile tilannetta, jossa sinulle jäi tunne, ettei kukaan välittänyt asiastasi tai sinusta ei ole pidetty huolta?

6. Onko sinulla ajatusta, miten nämä voisi hoitaa paremmin? Mitä toivoisitte?

Potilaspolun onnistumiset

7. Onko sinulle tapahtunut taudin hoidossa jotain erityisen hyvää tai muuta positiivista? Kerro esimerkkejä.
a) Miten reagoit? Mitä teit?
b) Kuka teki mitä?
c) Mitä odotit tapahtuvat, mitä ei tapahtunut, mitä tapahtui?

d) j) Miltä sinusta tuntui?
e) k) Mitä tästä seurasi?
f) l) Mistä tämä johtui? Onko sinulla ajatusta, mistä tämä johtui?

8. Kuvaile tilannetta, jossa sinulle jäi tunne, että sinusta pidettiin erityistä huolta?

9. Onko sinulla ajatusta, miten tällaisia tilanteita voisi luoda lisää? Mitä toivoisitte?

Potilasjärjestöt

10. Miten potilasjärjestöt ovat näkyneet tautisi hoidossa ja potilaspolussasi?

Kommunikaatio (Soveltuvin osin, jos ei ole aikasemmin tullut esille)

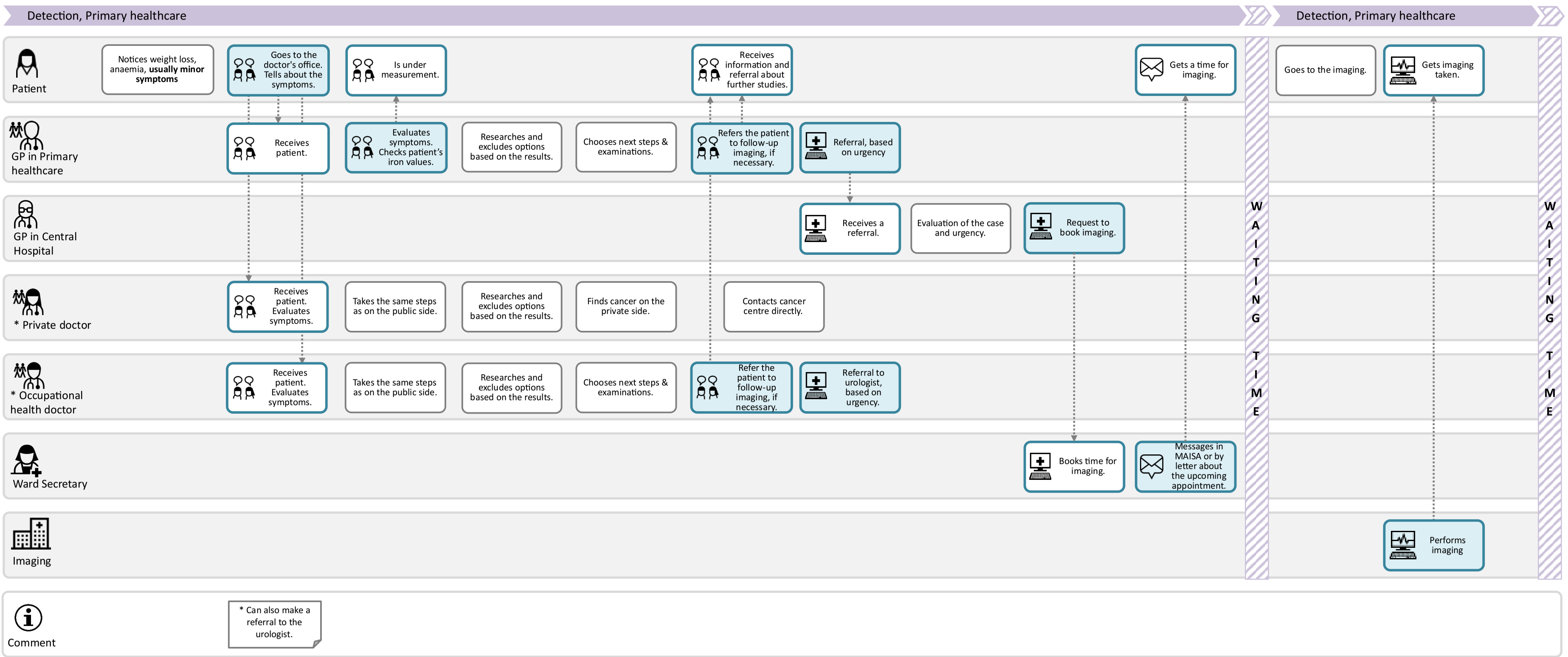
11. Miten olet yleisesti yhteydessä terveydenhuoltojärjestelmään?
12. Tuntuuko yhteydenpito koordinoidulta tai fragmentoituneelta?
13. Koetko, että sinulla on pääsy kaikkeen tarpeelliseen tietoon?

Dokumentaatio

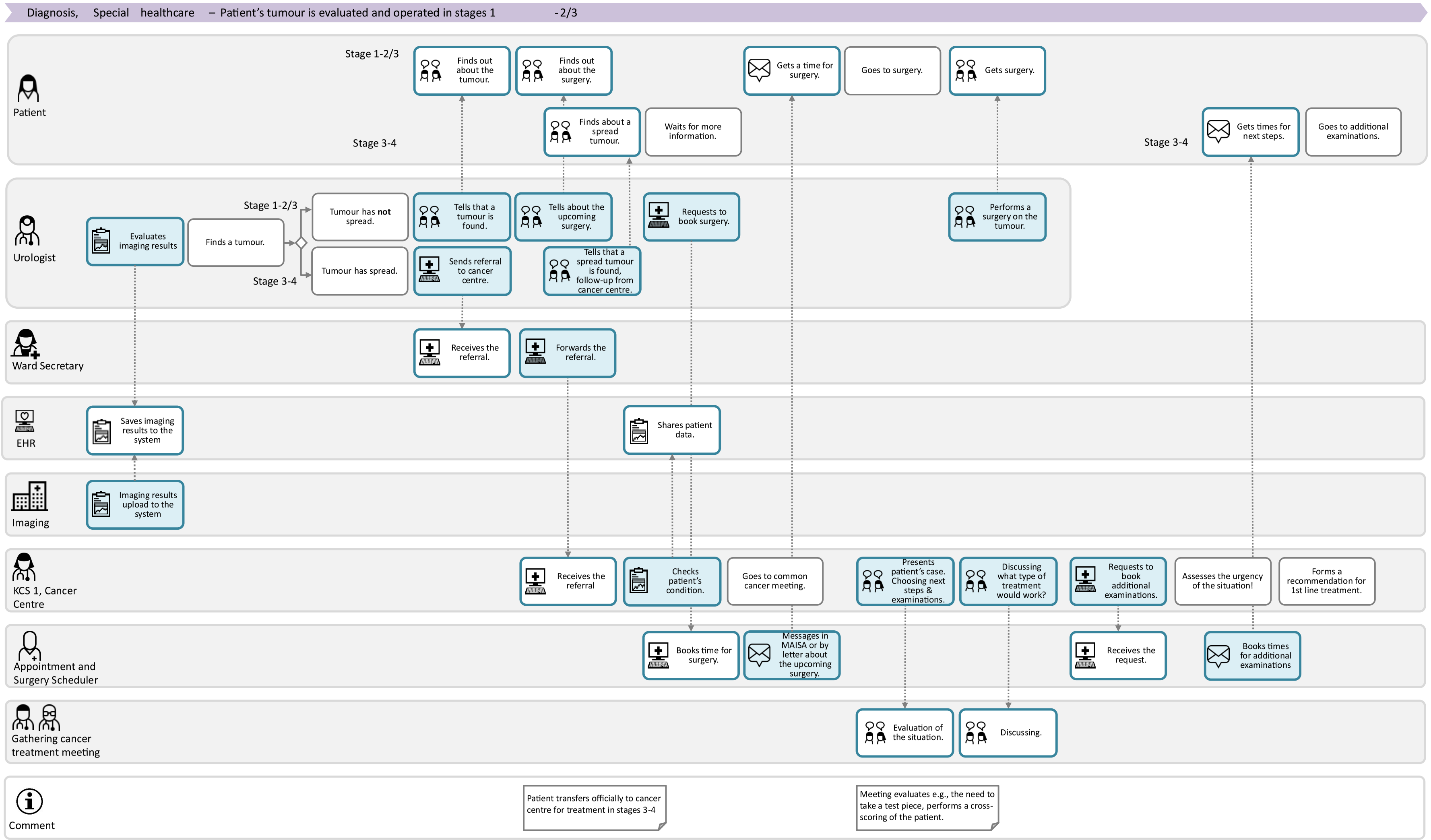
14. Pidätkö kirjaa sairauteesi liittyvistä asioista? Miten?

C. Kidney Cancer Care – CJML models

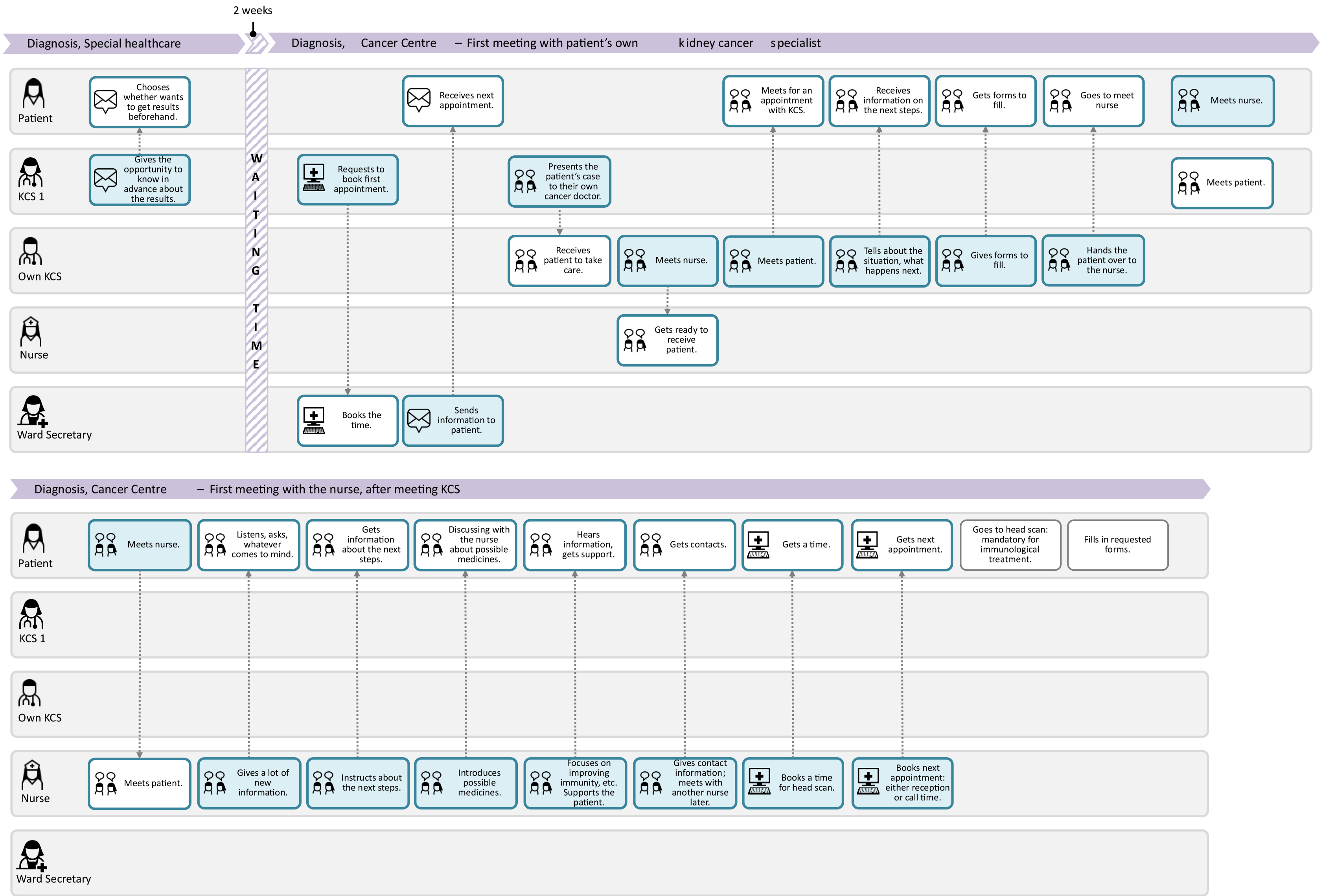
Model 1 – Detection
Model 2 – Diagnosis part 1
Model 3 – Diagnosis part 2 and 3
Model 4 – Treatment
Model 5 – Post-Treatment Survivorship
Model 6 – End-of-Life Care
Model 7 – Initial communication disruptions
Model 8 – Treatment disruptions
Model 9 – Kela Reimbursement Process



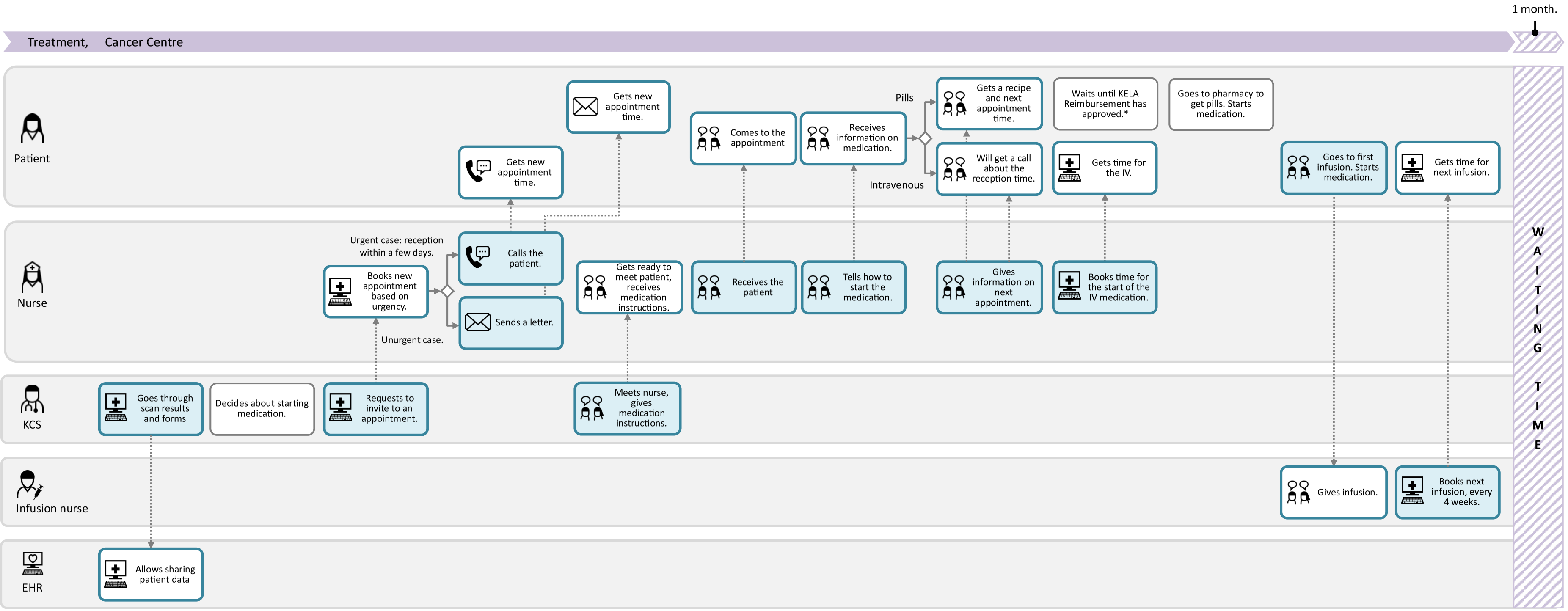
Model 1: Detection



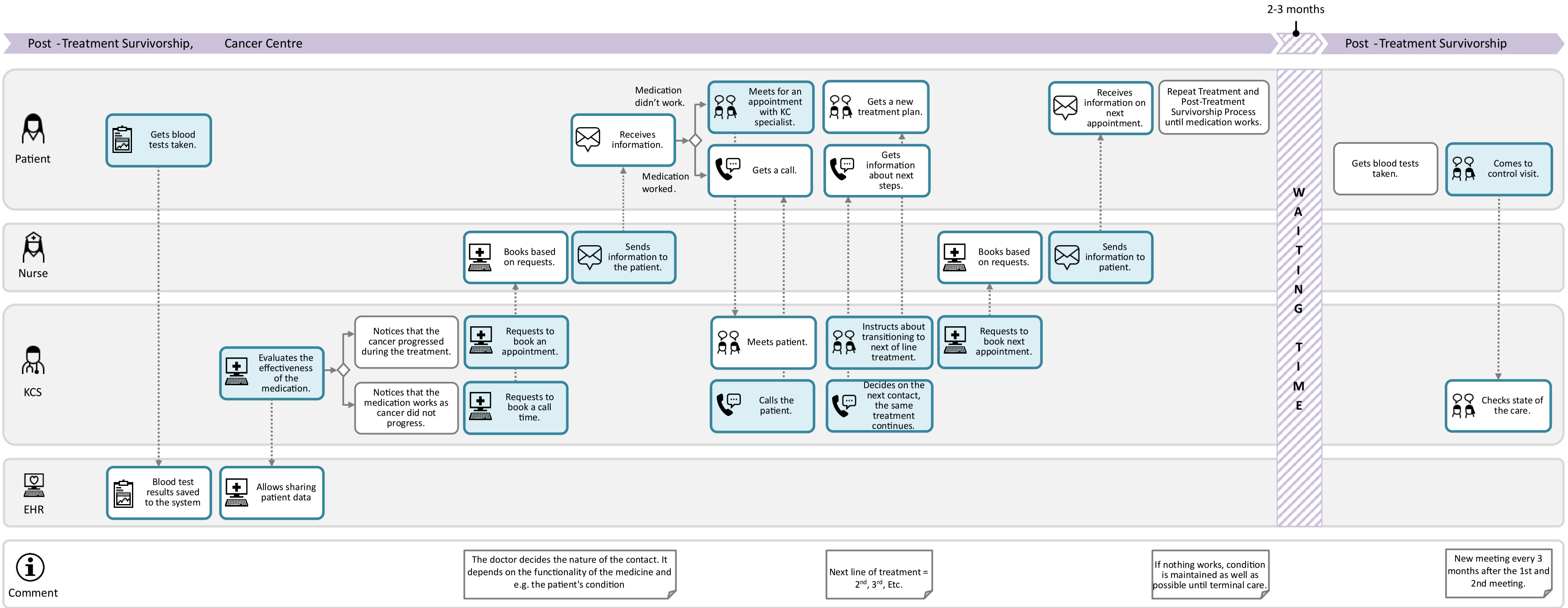
Model 2: Diagnosis 1/3



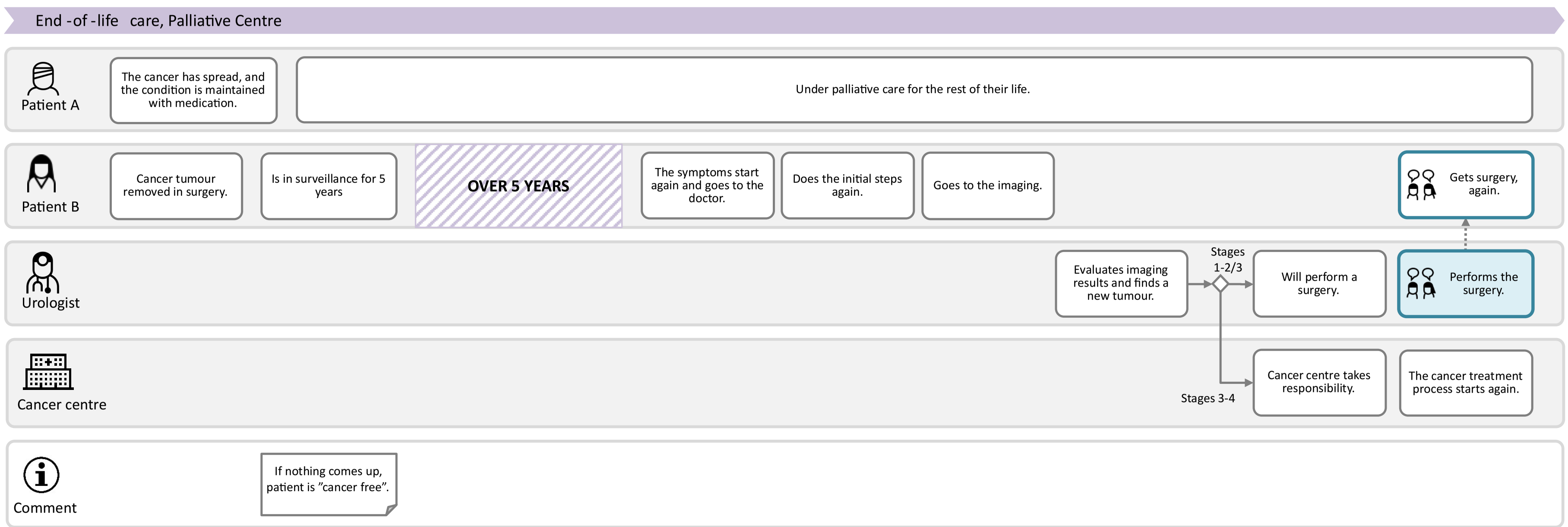
Model 3 & 4: Diagnosis 2/3 and 3/3



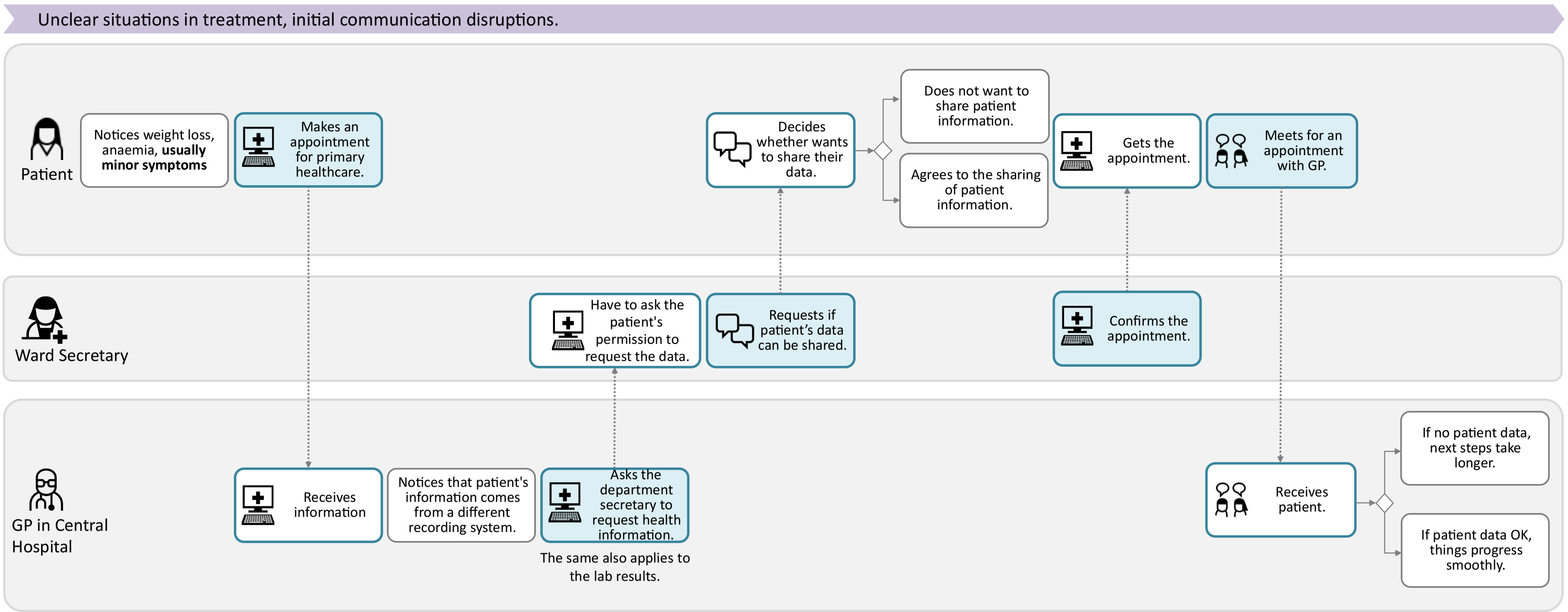
Model 4: Treatment



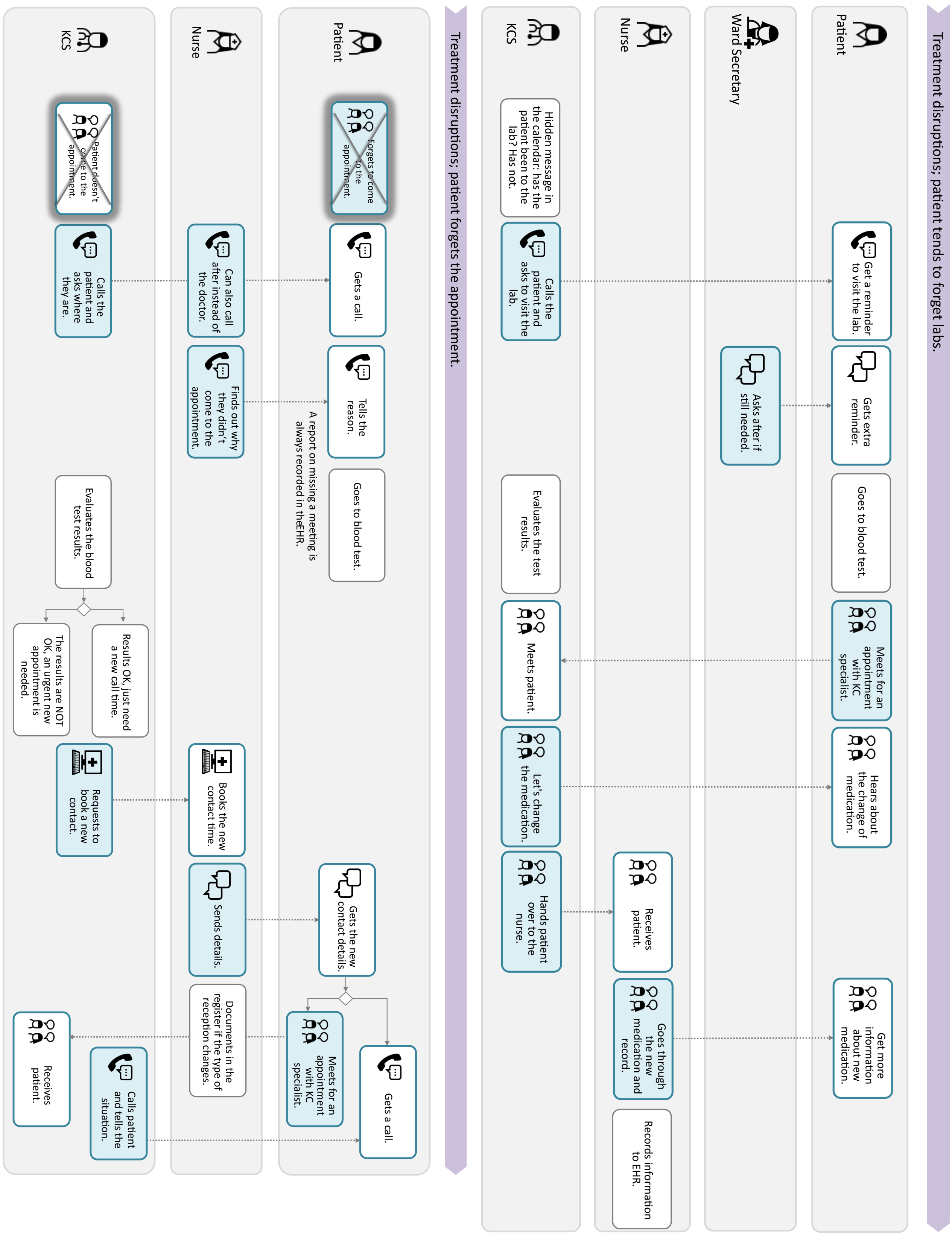
Model 5: Post-Treatment Survivorship



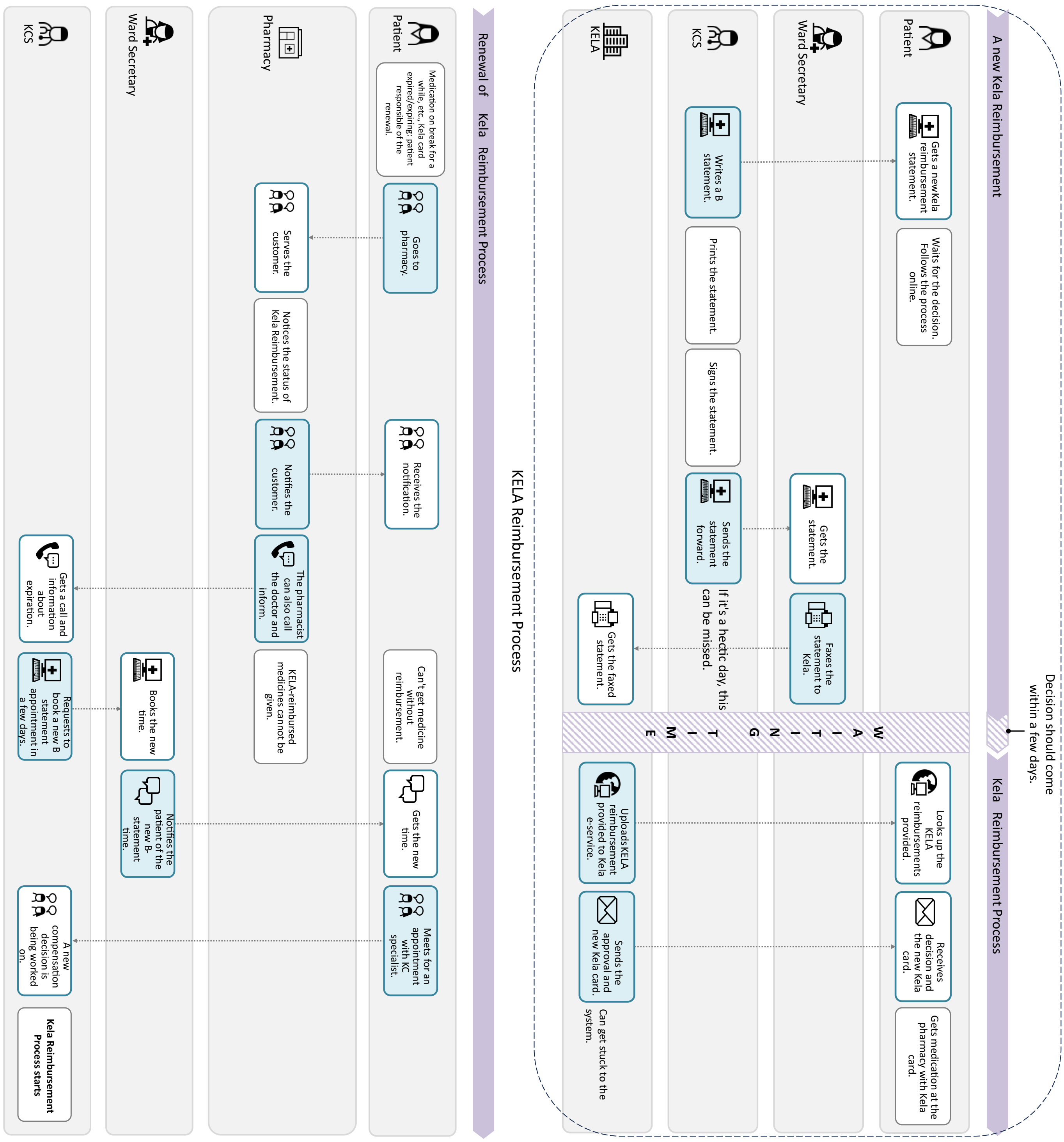
Model 6: End-of-Life Care



Model 7: Unclear situations in treatment, initial communication disruptions



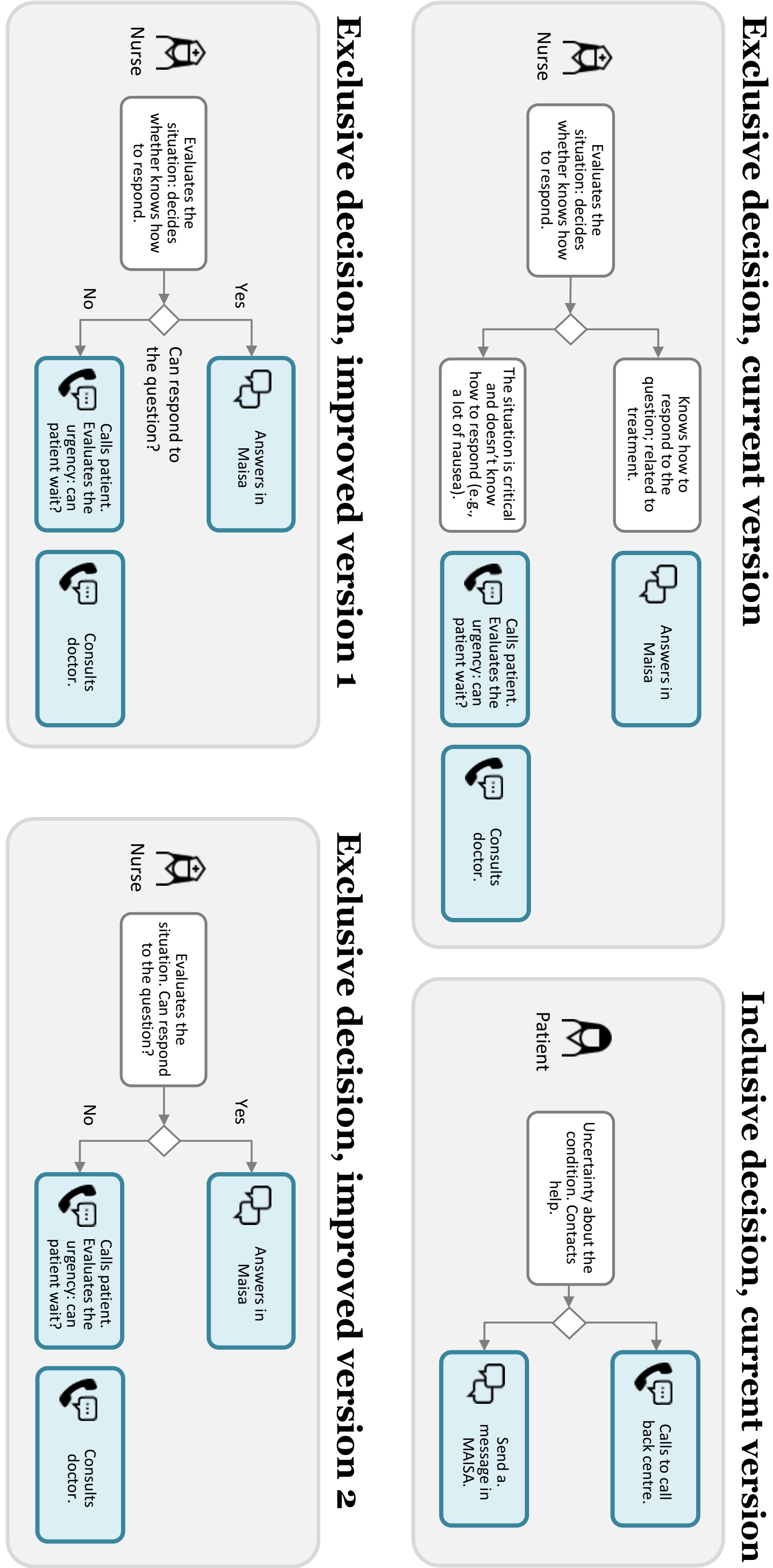
Model 8: Treatment disruptions, patient forgets labs



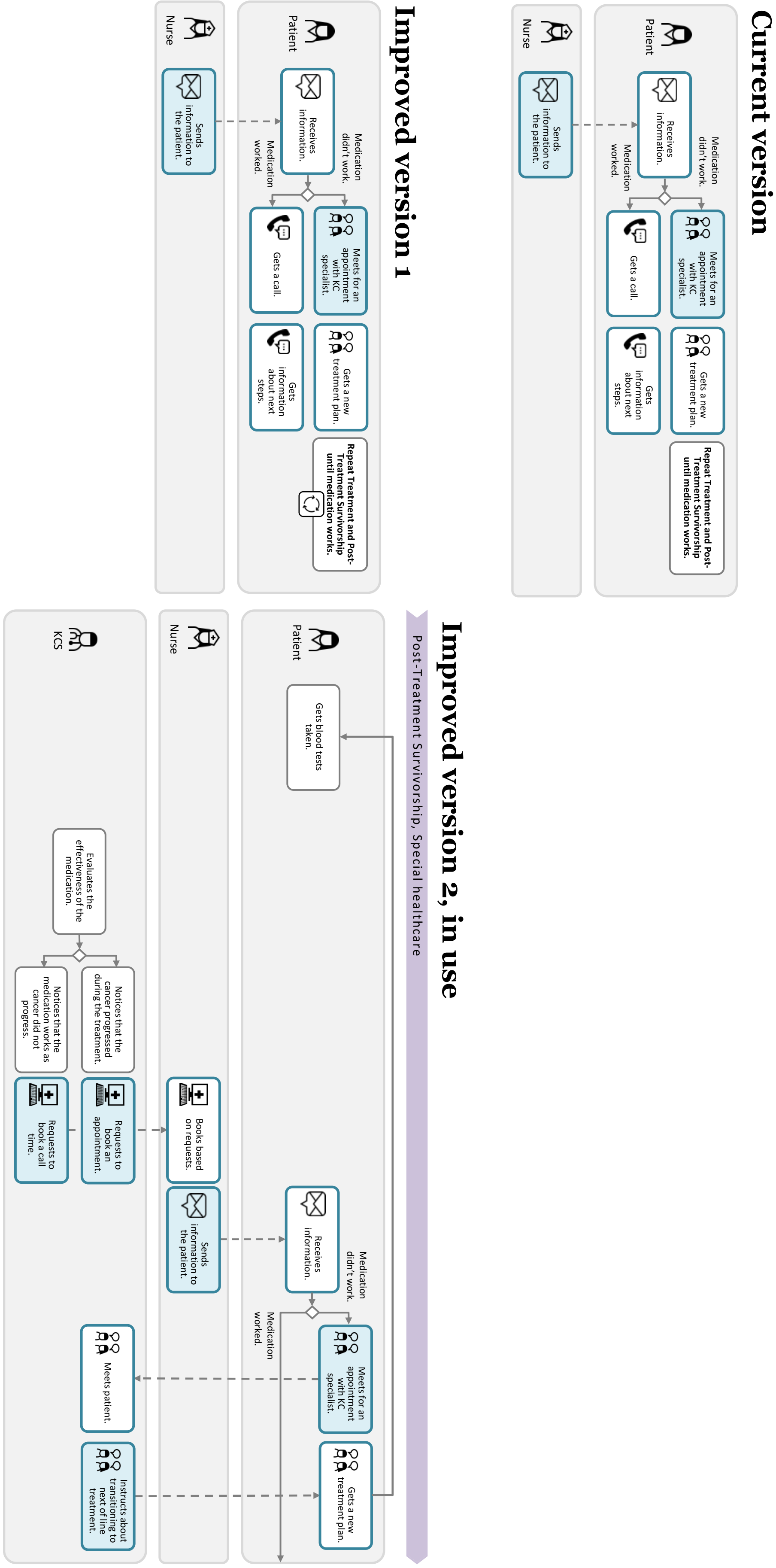
Model 9: Kela Reimbursement Process

D. Additional, created CJML development materials

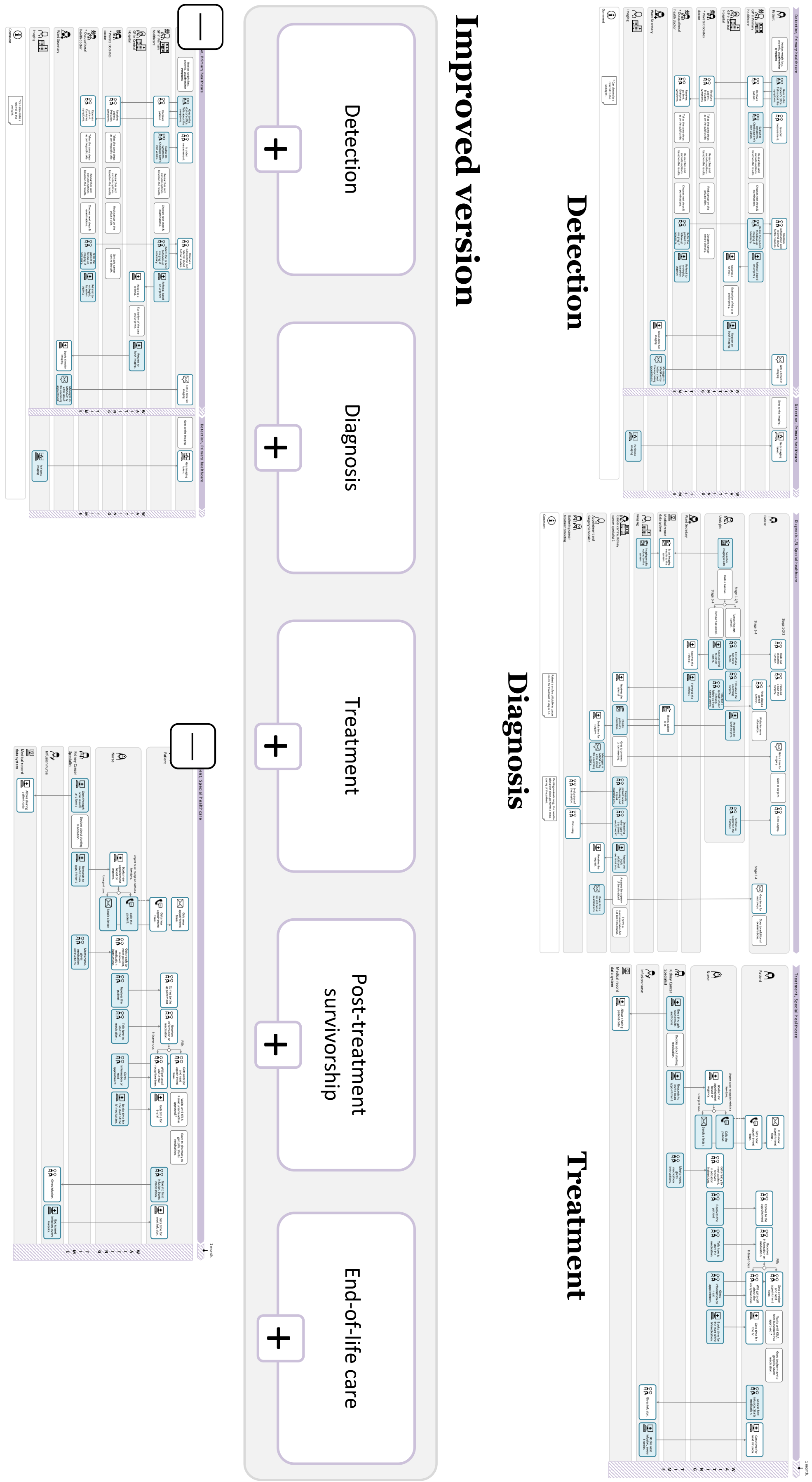
Proposal 1 – Decision point
Proposal 2 – Looping mechanism
Proposal 3 – Modules
Proposal 4 – Sub-process
Proposal 5 – Data object
Proposal 6 – Repeat action
Proposal 7 – Discussion point



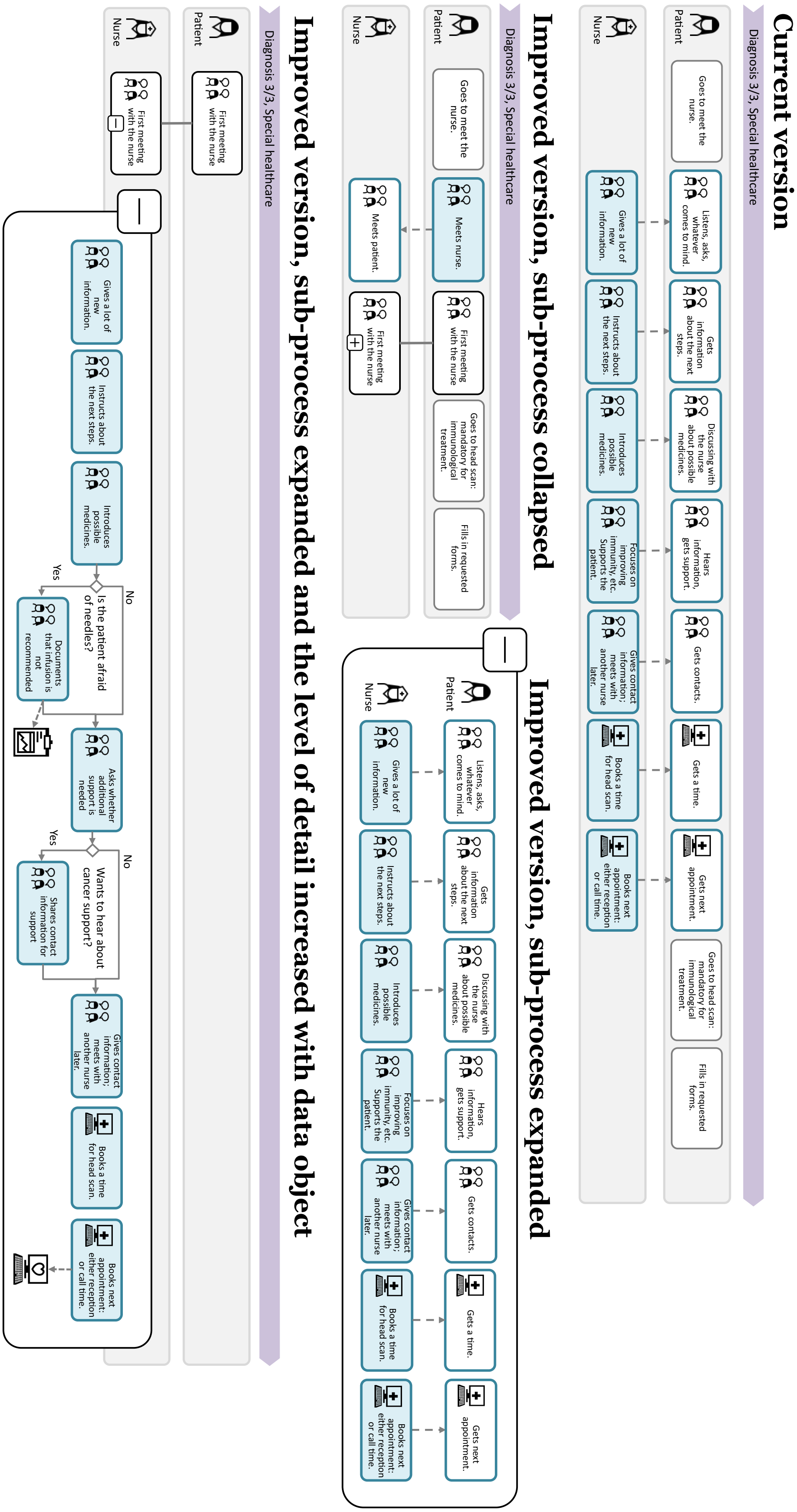
Proposal 1: Decision point



Proposal 2: Looping mechanism

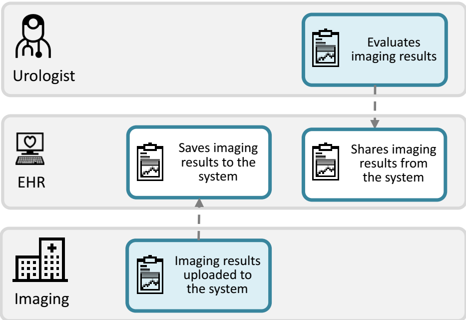


Proposal 3: Modules

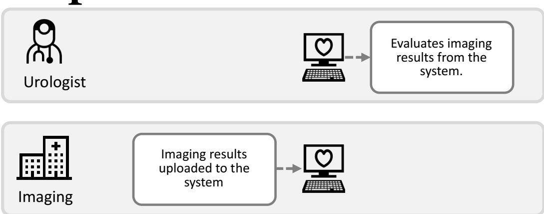


Proposal 4: Sub-process

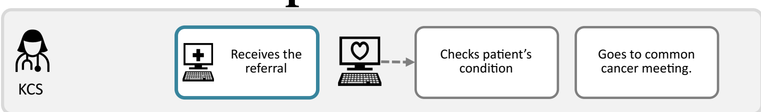
Current version



Improved version

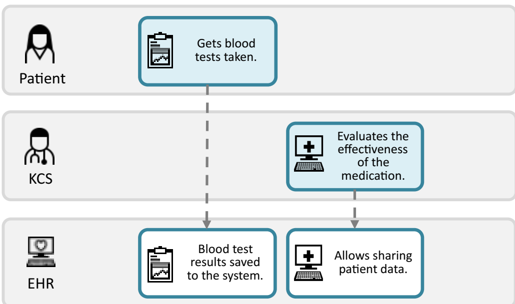


Another example

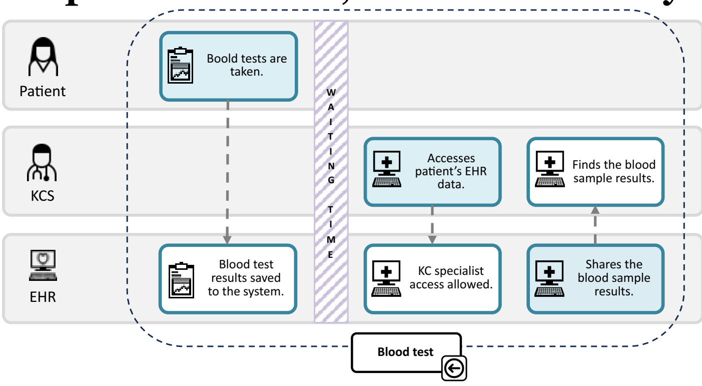


Proposal 5: Data object

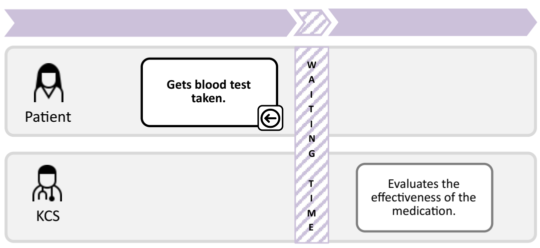
Current version



Improved version, blood test activity

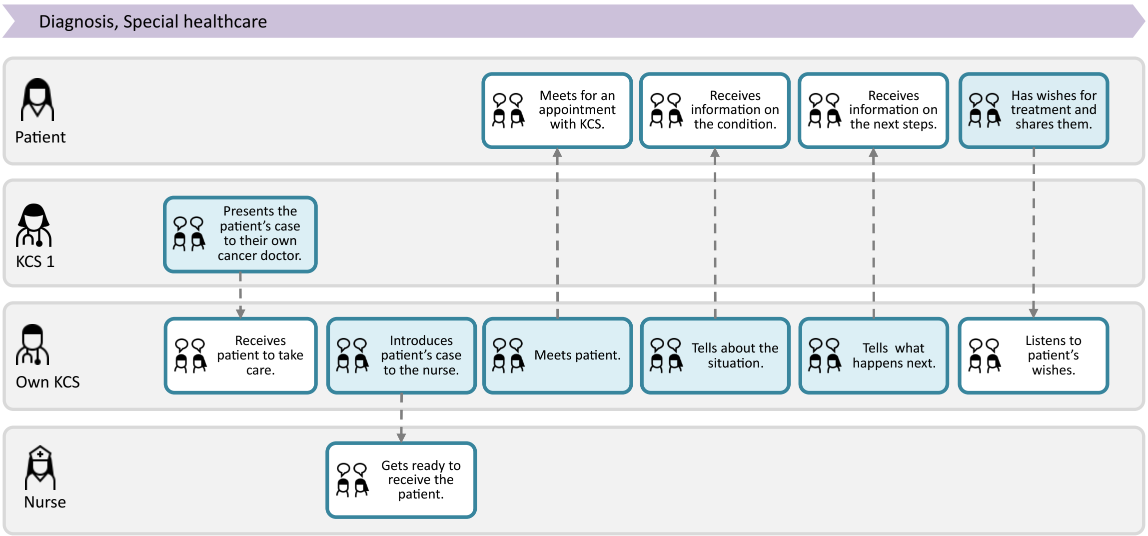


Improved version, next time

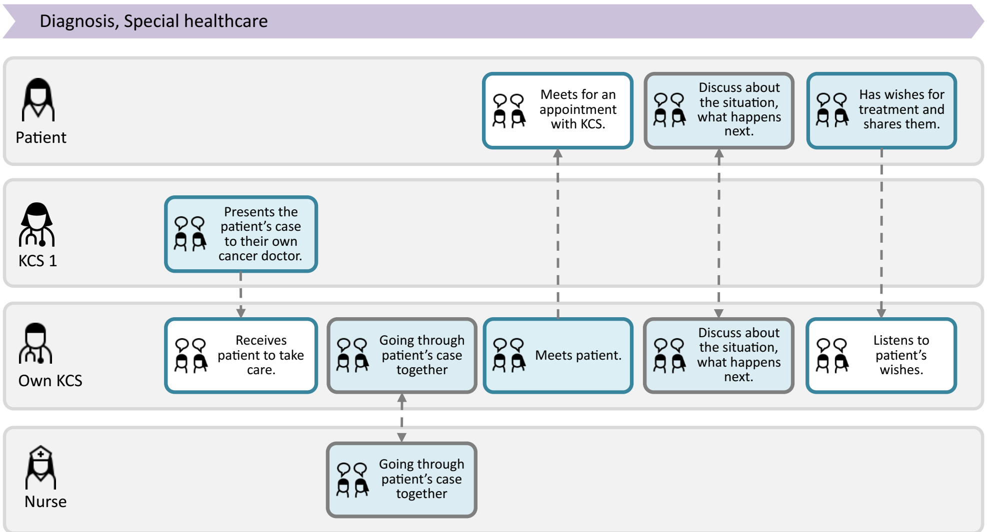


Proposal 6: Repeat action

Current version



Imroved version



Proposal 7: Discussion point