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Dual-Perspective Modeling of Patient Pathways: A Case Study on Kidney Cancer

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Abstract. Patient pathway has become a key concept in the organization of healthcare. However, the materialization and operationalization of pathways often focus on work processes of health personnel, clinical decision-making, and deadlines, contradicting the strong patient-oriented perspective that is inherent in their definition. In this paper, we introduce a patient-centered perspective of kidney cancer pathways, reporting on a dual-perspective strategy to map and model patient pathways. Utilizing a multi-method approach, we map and model pathways from the perspectives of both healthcare personnel and patients and investigate the feasibility of the Customer Journey Modeling Language (CJML) for modeling patient pathways. To prevent confusion, the planned pathway as seen from the hospital perspective and the actual pathway experienced by the patient are referred to as 'pathway' and 'journey', respectively. In the paper, we describe methods to engage with healthcare professionals and patients to collect the necessary information to create precise models, and we show how precise modeling of patient pathways requires the integration of several information sources. Moreover, the study underlines the value of examining pathways from a dual perspective, as the two perspectives corroborate and supplement each other, illustrating the complexity of patient journeys. Finally, the findings provide insights into the feasibility of CJML, firstly underlining that the usefulness of visual models is context-dependent, and secondly, suggesting that the methods and subsequent visualizations may be useful as organizational, instructional, and communicative tools.

Keywords: Patient Pathway · Patient Journey · Customer Journey Modeling Language (CJML) · Feasibility Study

1 Introduction

Patient pathway has become a key concept in the organization of healthcare, intended to address issues pertaining to coherency, seamlessness, and accountability in a system with increasing complexity [1, 2]. Understanding and representing patient pathways is essential in healthcare, as it helps identify potential bottlenecks and informs targeted interventions to improve patient care [3]. Moreover, while patient pathways are mainly used

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within hospitals, their use can also strengthen coordination between healthcare actors. A related concept is the patient journey, which takes the perspective of the patient throughout the pathway. Patient journey mapping is increasingly being adopted in healthcare settings to provide insights into the patient experience and to support communication with patients [4].

For simplicity, in the following, we use the term 'patient pathway' to describe pathways as designed by the healthcare system and the term 'patient journey' to describe actual, individual patient encounters throughout an illness period. We, however, maintain a patient-centered perspective for both. While many definitions of patient pathways suggest some level of patient-centered perspective [5], pathways tend to focus on clinical guidelines and other work processes behind the line of visibility of the patient [6]. As patient pathways involve numerous stakeholders and intricate decision-making processes, selecting a modeling approach that effectively captures both patient-provider interactions and the coordination of healthcare services is crucial to ensure the delivery of patient-centered care.

The complexity of healthcare processes, along with the need for effective communication and production planning, has led to a growing interest in using modeling languages to represent patient pathways. Several modeling languages have been used, including Unified Modeling Language [7], Business Process Modeling Language [8], extensions of such languages [9], Customer Journey Modeling Language [10], and a multitude of less formal patient journey maps [4], each with their strengths and weaknesses. The use of modeling languages for documenting patient pathways can reduce variability, help facilitate interdisciplinary collaboration, streamline decision-making processes, and ultimately improve patient outcomes [2, 5].

In this study we focus on the feasibility of the Customer Journey Modeling Language (CJML) for modeling of patient pathways, as planned by the healthcare system, and patient journeys, as experienced by individual patients. Offering a vocabulary, a metamodel, and purpose-specific diagrams, CJML is equipped with journey-specific constructs including touchpoints, actors, channels, phases, and user experiences [11]. CJML's patient-centric approach makes it particularly relevant for modeling patient pathways in healthcare. However, CJML may need adaptation to address the complexity and specific nuances of healthcare processes, as well as the interactions between healthcare institutions and personnel. Hence, there is a need for more in-depth research on CJML in healthcare contexts, including how it may be adapted and improved to suit the specificities of healthcare contexts.

Using kidney cancer as a case study, we explore how patient pathways and journeys can be identified from a dual perspective (both healthcare personnel and patients). We investigate how CJML can be utilized to visualize and compare these pathways and journeys. Additionally, we examine its application in healthcare settings, providing in-depth insights into the pathways and journeys from both perspectives, thereby enabling comparison. In specific, we address the following research questions:

1) How may we identify and make precise models of patient pathways and patient journeys using CJML?
2) What insights do we gain by a dual perspective exploring patient pathways and patient journeys?

3) How feasible are the CJML models in a healthcare setting?

To address these research questions, we present a case study of kidney cancer care conducted by health service researchers and medical doctors at a major university hospital in Norway. Kidney cancer typically develops slowly and is often detected incidentally during investigations for other conditions [12]. The involved hospital treats approximately 100 kidney cancer patients annually. The vast majority of these patients undergo either partial or radical nephrectomy. This study aims to contribute to the ongoing discourse on the application of modeling languages in healthcare and emphasize the importance of patient-centered approaches in representing and understanding patient pathways.

2 Methods

The study adopted a multi-method approach dominated by qualitative research methodology. The first phase of the work was conducted in two parallel streams: 1. Detailed insights into patient pathways (healthcare's perspective) and 2. A longitudinal study of patient journeys (patient's perspective), see Fig. 1. Based on this, we modelled the kidney cancer pathway and patient journey using CJML. In the second phase the feasibility of CJML in healthcare settings was evaluated.

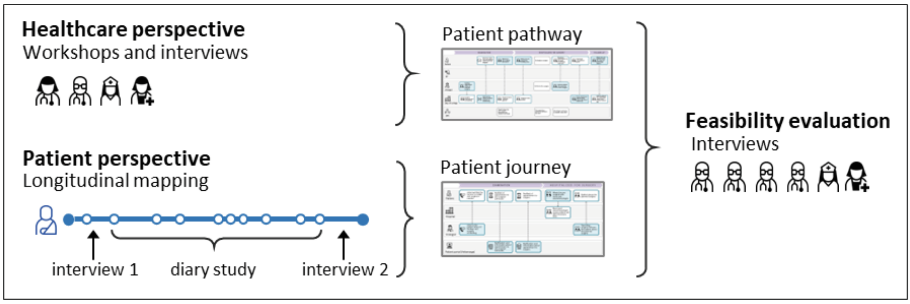

Fig. 1. Principal sketch of the study.

2.1 Recruitment

Healthcare personnel were recruited by one of the authors, while patients were recruited through medical doctor(s) involved in their treatment. A doctor in charge of kidney cancer treatment presented the study to selected patients, inquiring about their interest in participating and obtaining their consent to provide their name and contact information to the research team. If patients consented, the doctor called the research team and provided name and contact information to patients. A researcher then contacted the patient regarding participation in the study. After patients had formally given their informed consent, they were invited to a start interview. Patients were recruited purposefully shortly after they had been diagnosed with kidney cancer, and prior to surgery. Digital literacy was a requirement for participation.

The study meets the requirements of data protection legislation and research ethics and was approved by regional and institutional ethics committees. Participation in the study was voluntary and based on informed consent. To guarantee anonymity, we have used fictitious patient names and altered certain details of the patient journey.

2.2 Mapping and Modeling of Patient Pathways with Healthcare Personnel

The mapping of the patient pathway was conducted through a combination of the following activities: information search, observation, and workshops involving relevant healthcare personnel. Firstly, we carried out a desktop study reviewing all available material on national care pathways for kidney cancer. Second, we had several meetings with healthcare personnel at the Department of Urology, Oslo University Hospital. First, we had two virtual meetings with two doctors in the department, where we described the project. After these two meetings we were invited to observe a multi-disciplinary team meeting (MDT) where 10–15 doctors discuss the patients and decide on treatment. Then we arranged two workshops with two urologists to pinpoint the detailed kidney cancer pathway and had two shorter meetings with medical secretaries at the Department of Urology.

The goal of the workshops with the urologists was to get a detailed description of the patient pathway for kidney cancer, from diagnosis to treatment, from a hospital/department-level perspective. In the first workshop, we asked the urologists to describe the process from diagnosis to treatment. The workshop was taped and later transcribed, and we also took notes during the workshop. Based on these insights, we created an initial sketch of the kidney cancer pathways, highlighting areas that were unclear or required further investigation. This initial sketch served as the foundation for a second workshop with the urologists, aimed at verifying and specifying the description of the kidney cancer patient pathway. Again, we taped the discussion in addition to taking notes. Following this, we revised the pathway description, and subsequently sent it to the two urologists for feedback. In the next step, we used these data and pathway descriptions to model the kidney cancer patient pathway, using CJML. Hence, the analysis has been carried out as a continuous and iterative process, where we have collected data and, based on this, sketched out initial overviews of the pathway, before we have shown these initial overviews to practitioners, collected more data and revised the sketch of the planned pathway.

2.3 Mapping and Modeling of Patient Journeys

Patients were recruited for a longitudinal study that included an initial interview, a diary designed to map the patient journey in detail, and a debrief interview (cf. [13]).

Start Interview: The primary aim of the start interview was to get detailed information of the participant's patient journeys up to that point, including all contacts with healthcare services. The interviews were recorded and later transcribed, and all touchpoints were logged in a spreadsheet.

Diary: The primary goal of the diary was to collect the patient's touchpoints in real-time as they occurred. There are several advantages of using diaries: they enable continuous updates and facilitate longitudinal studies without too much intrusion in

patients' daily lives, they reduce the time between an occurrence and the account given of it, and they capture a level of detail that is difficult to achieve through interviews alone (cf. [14, 15]). Patients were presented to the diary and instructed in how to fil it in at the end of the start interview. They were asked to make an entry in the diary every time i) they had contact with healthcare services, not only consultations but also confirmations and reminders of appointments, and ii) they undertook an activity relevant to their illness, such as for example information retrieval. Moreover, for each diary entry they were requested to fill in date and time, who they had been in contact with and the communication channel used (e.g. SMS or face-to-face), provide a detailed account of the event and their experience of it, and rate their overall experience of each entry on a scale from 1–5. In practice, the diary was a Word document that included instructions and a table with four columns—date/time, actor/channel, description of touchpoint, and rating—and unlimited rows, where each row represented one touchpoint. To secure as detailed diaries as possible, patients received reminders to fill in their diary approximately every two weeks and were asked to regularly email us their diary with new entries. The responsible researcher continuously logged these diary entries into a spreadsheet and noted any questions, such as on missing information that needed clarification during the debrief interview. Thus, the analysis started during data collection. After patients had logged their activities in the diary for 2–4 months, we scheduled a debrief interview.

Debrief Interview: The primary goal of the debrief interview was to review the diary entries to ensure that all relevant information was included. During the debrief interview, the interviewer went through the touchpoints collected in the start interview and the diary and requested additional information where necessary. After finalizing and transcribing the debrief interview, the spreadsheet with touchpoints was updated. This updated spreadsheet was subsequently used as the starting point for modeling the patient journey.

Four kidney cancer patients were part of the study. However, in modeling the patient journey further below, we focus on the patient journey of one patient, from initial symptoms through surgery to scheduling of semi-annual checks, covering a period of five months. The patient was recruited to the study about two months after the initial symptoms and participated in the study for app. three months. Hence, the first phase of the patient journey, from initial symptoms until surgery, is documented in retrospect, through interviews and retrospective diary entries.

2.4 Feasibility Evaluation

In exploring the application of CJML to model patient pathways and their utility in healthcare settings, we interviewed four urologists (P1-P4), a cancer coordinator (P5), and a patient coordinator at the hospital admissions office (P6). We asked them to reflect on and evaluate the feasibility of our diagrams of the patient pathway (Fig. 2) and patient journey (Fig. 3). Participants had the opportunity to review the diagrams both before and during the interview. They were asked about their initial impressions of the diagrams, the extent to which they found the diagrams useful and comprehensible, and to reflect on how such visualizations may be used. Moreover, participants were asked whether important information was missing in the visualization of the kidney cancer patient pathway. Finally, at the end of the interview participants were asked to rate the

ease-of-use and the usefulness of the diagrams on a scale from 1 to 5, with the numbers signifying the following: 1 to a very small extent, 2 to a small extent, 3 neither/nor, 4 to a large extent, 5 to a very large extent.

The interviews were carried out on Microsoft Teams in September and October 2023, recorded, and automatically transcribed. The interviewer also took notes during the interviews. Immediately following each interview, key information, including quotations from the audio file, was entered into a spreadsheet. The spreadsheet included responses to all interview questions. This provided an overview and facilitated comparison between participants. Based on this, we began drafting initial findings, which were later discussed and refined by the authors through an iterative process, that included revisiting audio recordings, and re-examining the spreadsheet and transcripts.

3 Results

In this section, the results of our study are presented. First, the kidney cancer patient pathway, as seen from the hospital perspective, is described and visualized. Then, an actual patient journey, as seen from the patient perspective, is presented, before the two perspectives are compared. Finally, findings from the feasibility interviews are presented, exploring the use of CJML-based visualizations in healthcare settings.

3.1 Modeling of the Kidney Cancer Pathway (Healthcare Perspective)

Kidney cancer pathways vary between individuals and involve a large number of actors and touchpoints. In modeling the patient pathway, we have therefore made the following assumptions: We model the patient pathway of patients that seek medical care due to hematuria and exclude patients that are diagnosed amid investigations for other conditions. Moreover, we focus on the pathway for patients that undergo surgical treatment without post-surgery complications. All contacts and communication the patient has with the hospital is documented in the Electronic Health Record (EHR). To increase the readability of the diagram, we however only include EHR at selected points. Also, reminders of appointments are excluded. A model of the kidney cancer pathway using CJML is presented in Fig. 2.

Kidney Cancer Pathways. Standardized cancer patient pathways (CPPs) have been introduced in some countries with a guaranteed timeframe for timely diagnosis and treatment. From the hospital perspective, the planned pathway typically begins when they receive a referral from a general practitioner, although sometimes the patient is referred from another hospital. The patient has usually undergone a CT scan that revealed a renal tumor. A urologist at the Department of Urology then assesses the referral, and formally confirms the start of the kidney cancer patient pathway. Cancer pathway coordinators are responsible for arranging the appointments and acting as the patient's contact person. The patient is contacted via electronic mail (through the patient health portal), letter, or telephone.

A weekly multi-disciplinary team meeting (MDT) is held among healthcare professionals to discuss patient cases, aiming to provide the most comprehensive care possible, at the right place and time for each patient. A MDT Coordinator ensures that all patients

with a new cancer diagnosis are discussed, and their scans and biopsies are reviewed by the team. Leveraging the combined expertise of each team member and considering the specific needs of each patient, the MDT recommends a treatment plan. This plan is documented and discussed with the patient via a telephone call or a follow-up appointment. The outcomes of the MDT meeting can include surgery, biopsy, and active monitoring. In the following, we will focus on the planned pathway for patients undergoing surgical treatment.

Approximately one week prior to the scheduled surgery, the patient attends a pre-surgical assessment appointment with a surgical intern who evaluates the patient's health. The intern conducts a focused physical exam to ensure there are no medical risks that could predispose the patient to a medical emergency during the planned procedure. During the pre-surgical assessment, the patient also meets with a nurse. Finally, an anesthesiologist conducts a health assessment before surgery to gather information about any medical conditions the patient may have, their medications, and any previous experience with anesthesia.

The patient is admitted to the hospital either on the day of surgery or the day before. Upon arrival, they are greeted by a nurse who explains the processes and provides the patient with an identity bracelet to wear throughout their hospital stay. Additionally, the patient will meet the operating surgeon. After the surgery is completed, the patient is transferred to the recovery unit where they are closely monitored by a perioperative nurse. The patient meets with the surgeon to be informed of the outcome of the operation. Subsequently, the patient is moved to an inpatient room for postoperative care.

Patients are usually dismissed from the hospital 2–7 days after surgery. Upon discharge, they receive post-procedure instructions. Approximately 4 weeks after surgery, patients attend a scheduled appointment at the post-treatment clinic, where they are informed about the surgical pathology report and plans for further follow-up.

3.2 Modeling the Kidney Cancer Patient Journey (The Patient Perspective)

Here, we describe and model one of the actual patient journeys that was captured in the longitudinal study. This patient was diagnosed with kidney cancer following acute illness while travelling, which was unrelated to the cancer. In total, the patient journey included more than sixty touchpoints, necessitating several simplifications. Firstly, the diagram begins with the patient's initial contact with the hospital responsible for assessing and treating the cancer, thus omitting the early part of the patient journey as described below. Additionally, the following touchpoints have been omitted for simplicity: For each new hospital appointment, the patient was notified via SMS and through the patient health portal. Furthermore, 1 to 2 days before an appointment, the patient received SMS reminders. The resulting model of the patient journey is shown in Fig. 3.

Actual Kidney Cancer Patient Journey. Holger is in his fifties, works full-time, and lives a busy life. His patient journey began when he experienced severe abdominal pain while travelling. He visited a local emergency care unit and was subsequently referred to the nearest hospital, where he was diagnosed with an incarcerated hernia and underwent surgery. Simultaneously, a CT scan revealed a tumor in his kidney. Consequently, the

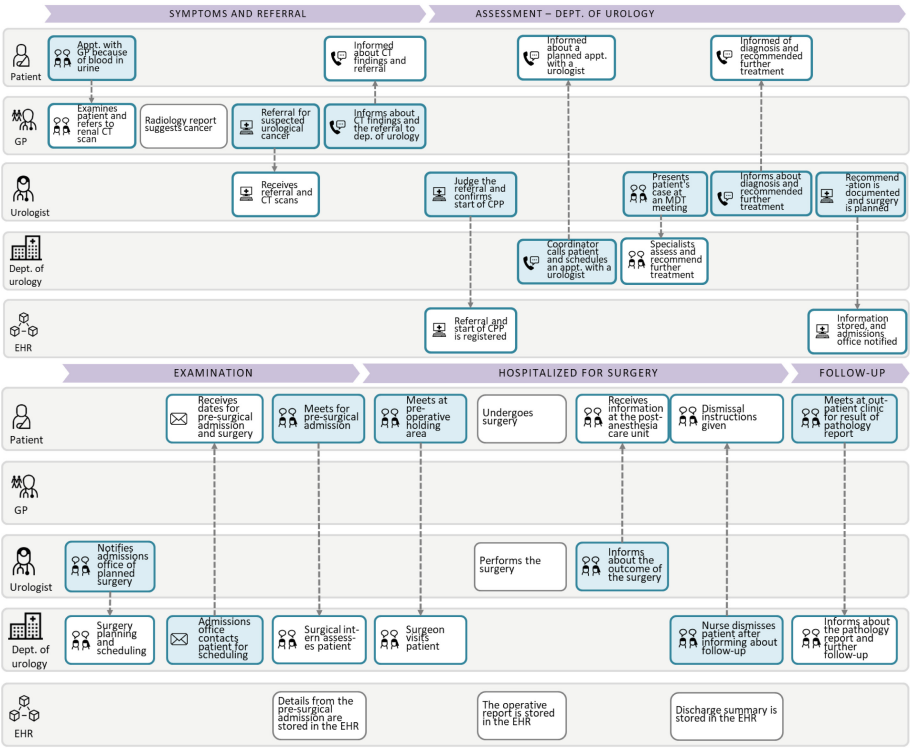

Fig. 2. Patient pathway—kidney cancer.

hospital referred the patient to his hometown hospital for follow-up and further evaluation. Approximately three weeks later, he was notified of a follow-up appointment at the Department of Urology at his hometown hospital. However, one day before the scheduled appointment, Holger received a phone call from the hospital stating that they had not yet received the CT images, necessitating a postponement of the appointment. After some back and forth, three days later, Holger received another phone call from the hospital, this time to schedule him for new CT images the following day. Consequently, Holger visited the hospital the next day for the CT scans and blood tests. Three days after this visit, a doctor from the hospital called him to discuss the need for a renal biopsy. Two days later, he returned to the hospital to undergo the biopsy.

Shortly after the biopsy, Holger was notified about a scheduled phone appointment with a urologist for the following day. However, the urologist called later than scheduled, and since Holger was unavailable, they postponed the call until to next day. During the rescheduled call, the urologist informed Holger that the tumor was malignant and recommended its removal through endoscopic surgery. Due to work obligations, Holger requested that the surgery be scheduled no sooner than four weeks later, which the urologist agreed to. A few days after the phone consultation, Holger received notifications about preoperative assessment and surgery appointments. Three weeks later, he attended

the preoperative assessment, where he met with a nurse and an anesthesiologist and had the necessary blood tests done.

A week and a half after the preoperative assessment, Holger was admitted to the hospital by a nurse and then had a consultation with the operating surgeon, who briefed him on the procedure. Shortly thereafter, he was escorted to the operating theatre by a nurse, administered anesthesia, and underwent the surgery. Hours later, he awoke and was moved to the ward, where he received continuous follow-up care from nurses. The day following the surgery, Holger had a consultation with a doctor (previously unknown to him). Throughout the day, he was under continuous care by nurses, including pain relief. The next day, Holger had a follow-up meeting with the operating surgeon, who briefed him on the surgery's outcome, further follow-up plans, and his dismissal from the hospital. Later that day, Holger was dismissed from the hospital and did not experience any further complications.

The day after he was dismissed, Holger was notified about a follow-up appointment at the hospital scheduled for one month later. Approximately ten days post-surgery he received an unexpected phone call from the operating surgeon, who informed him that he was now considered cancer-free. This was confirmed during the scheduled hospital appointment a few weeks later, after which Holger was put on a schedule for half-yearly CT-scans as a routine post-surgery check-up.

In total, Holger logged $n = 38$ touchpoints in the diary. For a majority of the touchpoints ($n = 27$), he rated his experience as 'very satisfied'. In an additional seven cases, he rated 'satisfied' or 'neutral', all of which related to the issue of transferring CT images between hospitals.

3.3 The Dual Perspective

The data and analysis presented above show that the two approaches corroborate and supplement each other. As illustrated above and summarized in Table 1 below, the patient pathway and the patient journey overlap in important respects, hence substantiating each other. For example, the actual patient journey includes the key steps presented in the visualization of the patient pathway (Fig. 2), such as being informed about diagnosis and recommended further treatment, receiving dates for pre-surgical admission and surgery, meeting for pre-surgical admission, being informed about the outcome of the surgery and meeting at outpatient clinic for results of the pathology report. Simultaneously, the planned pathway and the actual journey also differ. For example, in the actual patient journey, kidney cancer is found by coincidence and the patient is referred from a specialist rather from a GP, illustrating the diversity in patient journeys. Moreover, the patient journey includes touchpoints that are not presented in the patient pathway, such as CT images being re-taken, biopsy appointment, and the patient receiving an unscheduled phone call by the surgeon post-surgery, illustrating the complexity in actual patient journeys. This complexity is illustrated by Fig. 3 and further underlined when considering that the figure is a simplified version of the patient journey.

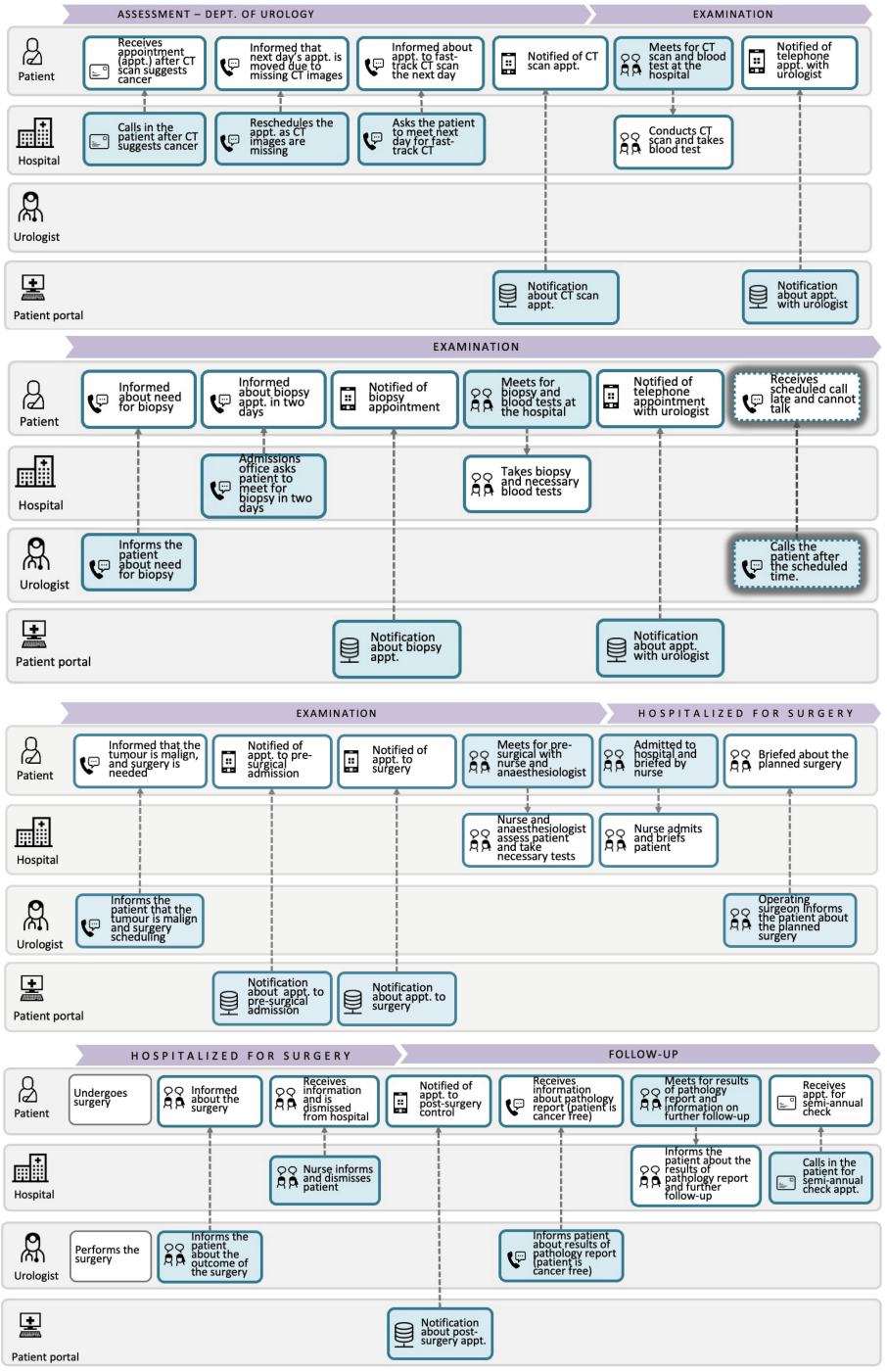

Fig. 3. Patient journey of a kidney cancer patient.

Table 1. Comparison of patient pathway and actual patient journey

Touchpoints that overlap	Additional touchpoints in patient journey	Additional touchpoints in patient pathway
- Notification of appointment with urologist - Phone appointment with urologist - Notification of appointment to pre-surgical admission and surgery - Pre-surgical admission - Surgery admission - Surgery - Information about outcome of surgery - Dismissal instructions - Meeting for result of pathology report	- CT images re-taken - Biopsy appointment - Receives scheduled phone call late, rescheduled - Hospitalization includes several touchpoints - Unscheduled phone call - Touchpoints including healthcare professionals beyond hospital dept	- Referral - Start of CPP - MDT meeting - Documentation and surgery planning

3.4 Feasibility Evaluation

We asked four urologists (P1–P4) and two coordinators (P5–P6) to assess the feasibility of the visualizations of the patient pathway (Fig. 2) and patient journey (Fig. 3). The findings show that the participants generally do not use diagrams or other visualizations of patient pathways as part of their work, although some have prior experience with similar ways of representing pathways. Hence, the findings indicate that visual representations of patient pathways are currently not much used in hospital settings.

Despite having little previous experience with visualizations of pathways, participants generally found the diagrams to be intuitive and easy to understand. Being asked to rate the ease-of-use of the diagrams on a scale from 1 to 5, the majority gave the rating 4 (two participants) and 5 (three participants), while one participant gave the rating 2 noting that he found the diagrams to contain too many boxes and too much information, making them complicated to read.

In terms of usefulness, participants did not consider the visual representations to be useful in their day-to-day work, noting that as experienced doctors and coordinators they are already familiar with the key points in the kidney cancer patient pathways, and in their daily professional lives they focus on the steps that they themselves oversee, such as surgery. A coordinator for example said that *"To me there is nothing new in this diagram. […] The diagram gives a good overview, but I cannot see that it would be useful for me in my work"* (P5). However, the participants pointed to how such diagrams may indeed be useful as organizational, instructional, managerial, and communicative tools. The participants in particular noted potential usefulness related to the following: to map current practices across roles and departments; to arrive at a common understanding across roles; to identify bottlenecks and increase efficiency; to communicate efficiency potentials to for example healthcare professionals, hospital managers, or health authorities;

to standardize and secure equal treatment to patients, and in training for new employees and in educational settings (see Table 2, below, for an overview). A urologist for example noted that:

> It may contribute to improve efficiency, coordination. You see that there are steps that could be slimmed down […] We complain all the time that there are large queues, but I also believe it is inefficient operations (P4).

Another urologist who occasionally had been part of a similar activity where everyone involved in a specific treatment wrote down steps and responsibilities on sticky notes, noted that:

> I think it is very useful if the right people sit together and together figure out how to do something about the pathway. [...] It is useful if all involved are meant to see the same problems. That is also why we do [the sticky note activity], so that everyone involved can agree on an idea, how something is to be done, and that all perspectives are taken into consideration (P3).

Hence, the findings point to how usefulness would depend on the context, the purpose, and the role and seniority of those using it. Granted this context dependency, participants generally found it challenging to rate the usefulness of the visualizations. For example, some gave the rating 1, relating usefulness to their day-to-day work, while others rated 4 or 5, relating usefulness to broader organizational, instructional, or communicative issues. One of the urologists pointed this out in noting that usefulness would depend both on the context and the motives for using it:

> If, for example, I was to present something for The Ministry of Health to point out that we should do so and so, this would be the way to do it. So, I would rate it anywhere between 1 to 5 (P3).

This also relates to the level of detail in visualizations, where the participants noted how the appropriate level of detail would depend on the purpose and the recipient. Some for example noted that if the visualizations were intended to quickly communicate the key steps in a kidney cancer patient pathway, for example to patients or other groups with limited previous knowledge, the current visualizations may be too detailed and complicated to read. Similarly, others noted that if visualizations were intended to communicate the complexity of patient journeys in educational settings, or to map out current practices, a high level of detail might be beneficial.

Being asked about whether such diagrams could be useful to show patients, the participants were generally skeptical, noting that individual patient journeys vary, diagrams of the patient pathway may feel overwhelming, leave patients with more questions than answers, and create confusion if the actual patient journey deviate from what is visualized in the diagram. One of the urologists said that "*No, I think it would confuse more than being beneficial*" (P4). Another one noted that: *"I am not so sure about that, because today patients are bombarded with information, they drown in information, and they are not able to deal with all the information"* (P1). Some of the participants, however said that very simplified diagrams with key touchpoints might be useful for patients.

Table 2. Areas of use for visualizations of patient pathways.

Organizational/managerial	Instructional	Communicative
- Map practices across roles, departments - Arrive at common understanding - Identify bottlenecks and increase efficiency - Standardize and secure equal treatment to patients	- In training for new employees - In educational settings	- To communicate efficiency potentials, e.g., to hospital managers, health authorities, healthcare professionals

4 Discussion

In this study, we utilized CJML to model a kidney cancer patient pathway from observations, workshops, and interviews with healthcare personnel, as well as a detailed patient journey of one patient from interviews and a longitudinal diary study. Moreover, we collected feedback from urologists and coordinators on the feasibility of using CJML modeled pathways in practical healthcare settings. Below, we discuss the key findings related to our three research questions. First, we discuss the effectiveness of our methods for precisely identifying and modeling patient pathways and journeys. Second, we discuss the insights provided by applying a dual perspective. Third, we discuss the feasibility of CJML models in healthcare settings.

Mapping the Patient Perspective. The longitudinal study offered a detailed view of the patient journey, capturing many of the touchpoints that patients experience. We find that the diary method, where patients log each new touchpoint, is well-suited as a basis for modeling patient journeys. However, the diaries alone are not sufficient to provide a full picture of the patient journey, as patients tend to forget to log some touchpoints, such as appointment notifications or phone calls with healthcare personnel. Therefore, interviews are essential to supplement and clarify diary entries, gather patients' assessment of touchpoints, uncover missed entries, and hence, to provide a fuller picture of the patient journey. For the patient journey detailed in this paper, about eighty percent of the touchpoints were logged in the diary, with the remaining twenty percent identified during interviews. This is consistent with previous findings, which suggest that informants typically report between 50–70% of touchpoints [16]. The diary method enriches the toolkit for collecting patient journey data, complementing focus groups (i.e., [17, 18]), surveys [19, 20], document analysis [21], and interviews (i.e., [22, 23]), by facilitating more detailed patient journey maps. Of the data collection methods available, the diary method ranks among the most detailed. However, the challenge with the method is that it is resource intensive, and there is a risk that participants drop out during data collection. Despite these challenges, our study reaffirms the method's suitability for accurately modeling patient journeys with CJML, thus providing healthcare personnel with an overview of what a patient journey may look like from the patient perspective, which they today largely seem to lack.

Relatedly, the method provides insights into patients' experiences with each touchpoint, which can be instrumental in identifying bottlenecks and improving healthcare services overall. An example of the metrics and presentation of patient experience can be found in [13]. By gaining knowledge on patient experiences throughout the patient journey and in relation to specific touchpoints, we obtain a richer, more detailed, and more dynamic understanding of patient experience as it evolves throughout a patient journey, compared to the snapshot provided by measuring patient experience at a single point during or after an illness period. Therefore, our method may be a valuable supplement to patient-reported experience measures (PREMs) [24]. The specificity of the measures entails that they capture particular challenges that patients face, making them well-suited as basis for improving healthcare services. Moreover, by offering insights into experiences over time, researchers can more accurately capture how the overall patient experience is shaped, and which factors that are most important to patients.

Mapping the Patient Pathway. Our study highlights the necessity of a iterative process to accurately map the patient pathway. This includes recurring workshops with healthcare personnel for data gathering and drafting initial pathway sketches, followed by meetings to review initial visualizations, where healthcare personnel provide feedback on the pathway's accuracy and completeness. Patient pathways are complex, and carrying out data collection in steps ensures that the data and subsequent visualizations are as comprehensive and accurate as possible. This approach aligns with current literature on the development of pathways [20].

The Dual Perspective. Our findings show that the dual perspectives corroborate and supplement each other. On one hand, the patient pathway and journey overlap in important respects, hence the two perspectives substantiate each other. On the other, their differences highlight the diversity and complexity of patient pathways, illustrating the importance of visualizations to provide an overview. The dual perspective yields insights unattainable through studying the pathway or journey in isolation. Studying patient journeys reveals a detailed picture of all the touchpoints that a patient indeed encounters. Moreover, we get insights into touchpoints across and beyond healthcare institutions and personnel throughout an illness period, and insights on patients' experiences with healthcare personnel, communication, and coordination. Conversely, studying patient pathways from the healthcare side provides visibility into aspects that are hidden from patients, such as electronic health records, internal procedures, meetings, organizational issues, and decision-making.

Feasibility. Our findings underline how the usefulness of CJML visualizations depends on the context. The results from interviews suggest that while healthcare personnel may not find such diagrams particularly useful in their everyday work, such models may be useful as organizational, instructional, managerial, and communicative tools, such as to map practices across roles, arrive at a common understanding, identify efficiency potentials, and communicate these to stakeholders, as well as in training and educational settings. Relatedly, the findings illustrate that the appropriate *level of detail* in visualizing patient pathways depends on the purpose and the intended recipient. For example, the appropriate level of detail is likely higher when representations are meant to provide an overview and identify bottlenecks within or across departments than when

visualizations, for example, are meant to communicate such bottlenecks and improvement potentials to hospital managers or health authorities. Moreover, if used in training or for educational purposes, very detailed visualizations may help healthcare personnel or students understand the complexity of patient pathways. Less detailed visualizations may be better suited if the goal is to provide an overview of the key steps in a planned patient pathway at a specific department or hospital. Hence, representations of pathways and journeys should have a clearly stated aim, with visualizations being adapted to the aim and the recipient. However, to get an overview of and be able to make relevant representations in different contexts, a detailed mapping of patient pathways would nevertheless be a prerequisite. In other words, all touchpoints may be important, but their importance in visual representations will depend on the context and purpose. This indicate a need to further formalize the modeling language so that, for example, touchpoints representing reminders may easily be omitted from visualizations.

Theoretical and Practical Contributions. Our results contribute to theory by highlighting the need for duality in healthcare systems modeling. Modern healthcare production systems are often designed largely from the production perspective [25], and although the importance of the patient perspective is often underlined, its role in the design of the service production system is often still small. Our results highlight the critical role of the patient in the design of healthcare systems, especially in long-term care processes. Considering a person with kidney cancer lives with the disease 24/7, how can we design a functional care system purely from the perspective of the actor who meets the person for a few hours every year? Practically, we contribute a concrete tool and example of how such a dual pathway model can be built and used to inform decision-making in patient processes. CJML is an openly available modeling tool with support resources available for healthcare professionals to make use of in their process improvement efforts.

5 Conclusion

In this paper we have examined the identification and modeling of patient pathways and journeys, the insights gained from applying a dual perspective, and the feasibility of CJML-based models in healthcare. The methodological approach, and the combined exploration of the healthcare- and patient perspective highlight the complexity of patient pathways and patient journeys, illustrating that visualizations can provide a valuable overview of this complexity. Although healthcare professionals may not find these visualizations crucial for daily tasks, our findings suggest that the methods and subsequent visualizations may be useful as organizational, instructional, managerial, and communicative tools.

The focus on one illness, a few patients, and a single hospital department allowed for an in-depth analysis of patient pathways and journeys. This approach has allowed us to explore how pathways and journeys can be precisely captured and modelled, how they compare, and the feasibility of CJML models in healthcare settings. However, the focus on a single illness from the perspective of a relatively limited number of healthcare professionals and patients is also a limitation. The insights provided in this paper should be explored further and tested in other contexts, with other illnesses, and

on larger samples. We maintain that our findings related to identifying and modeling patient pathways/journeys, and the feasibility of using these models in healthcare settings have value beyond kidney cancer care. Nevertheless, kidney cancer patient pathways may be relatively short and standardized compared to other illnesses, such as chronic diseases or other types of cancer, indicating a need for further studies focusing on other illnesses. In terms of feasibility, additional studies are needed to better understand the specific contexts in which visualizations may be useful and the appropriate level of detail for presenting patient pathways/journeys to different actors, such as patients, hospital administration, nurses, doctors, or even students. Relatedly, since the findings indicate a need for filtering touchpoints and providing visualizations at different levels of abstraction, future studies should further explore how the formalism of CJML can be extended to more effectively support the healthcare context.

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