Pathway Toolbox Handbook

A practical guide to modeling and analyzing patient pathways

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Pathway toolbox

SINTEF

PREFACE

This handbook introduces the Pathway Toolbox — a collection of methods and tools for modeling, analyzing, and improving patient pathways and patient journeys.

The toolbox is publicly available at www.cjml.no/health. It is intended for clinicians, coordinators, technologists, researchers, and others involved in healthcare, and is designed to support more patient-centered, transparent, and well-coordinated pathways and journeys. It includes structured methods, templates, practical guidance, and example cases.

The Pathway project (2021–2025) was led by SINTEF Digital, Norway in collaboration with the University of Oslo and Aalto University in Finland. Most case studies were conducted at university hospitals in Oslo and Helsinki. The project was funded by the Research Council of Norway, grant no. 316342.

UiO : Universitetet i Oslo

1 OVERVIEW

Healthcare services are often described through patient pathways, plans and internal process charts. However, the concept of patient pathways is often poorly defined, abstraction levels are highly variable, and methods to describe and analyze pathways are virtually non-existent. A clear and structured modelling approach can be useful for exploring how healthcare services are delivered over time, and for comparing the planned pathway with the actual patient journey as experienced by the individual. This handbook presents the background, introduces PJML, provides guidance on using the toolbox, and discusses its evaluation and limitations.

1.1 What is Patient Journey Modeling Language (PJML)?

PJML is a visual modelling language. It comprises terminology, syntax, and visual elements like flow elements and connectors. PJML builds on the established Customer Journey Mapping Language, and extends it for the healthcare domain. The added "P" emphasizes the patient as the primary end user. Accordingly, PJML primarily focuses on patient-facing interactions, while internal processes, workflows, and coordination activities are only represented when they directly impact the patient journey.

1.2 What is PJML used for?

PJML can be used to describe and document patient pathways, understood as health service production plans. With PJML they can be visualized for quick comprehension and modified for individual patients and circumstances. For routine and predictable cases protocols and checklists can be developed. For complex cases, such as chronic conditions and multimorbidity, long-term care relations can be planned and monitored. PJML is also used to describe and document patient journeys, how a pathway was executed, what happened, and how it was experienced by a patient. PJML can be used for analytics and improvement. Registry data can be aggregated to analyze how patient journeys correspond to pathways, i.e. what was planned, what was done, and what happened. Further, individual patient journeys can be explicated to identify preventable disruptions.

1.3 How is PJML different?

PJML is inherently patient-centred, following the sequence of events as they unfold from the patient's point of view. It also incorporates patient experience, as reported by the patient, making it possible to capture both what happens and how it is perceived. In contrast, other modelling languages are typically organization-centred or process-centred, where human roles are not always explicit.

PJML is integrative, crossing organizational units and levels of care. Other modelling approaches often focus on a single organizational unit, such as a hospital or a ward, and may not include what happens before or after. PJML supports an end-to-end perspective from the patient's point of view.

1.4 Who should use PJML?

PJML is designed to be used by a wide range of stakeholders, including healthcare professionals, coordinators, administrative and IT personnel, researchers, process owners, and others involved in healthcare.

1.5 Key concepts

- Patient pathways – clinical and care plans
- Patient journeys – what was done, what happened, and how it was experienced
- Actors – patients, healthcare professionals, supporting staff, and significant others
- Touchpoints – service provider – patient interactions
- Patient experience – behavioral, cognitive, emotional
- Deviations from what could be reasonably expected - Patient journey disruption

2 BACKGROUND AND THEORETICAL FOUNDATION

This chapter summarizes the conceptual foundations of patient process analysis and management. It builds on the Healthcare operations management (HOM)[1] body of knowledge, which in turn draws on Service science and Industrial management. Details and the theoretical contributions of the PATHWAY project are presented in Chapter 3 and in the case studies.

2.1 Why processes?

Processes become necessary when a patient's concerns can't be handled within one care relation as one uninterrupted service event. Relevant diagnostic information (lab tests, imaging) may not be available, so the patient is asked to come back after these have been acquired. The condition may require monitoring and follow-up. The first caregiver may not be able to perform all the needed things but must refer the patient to another specialist or facility. Care is split in terms of:

- time (schedule of appointments),
- competences and corresponding actors (referrals to specialists),
- locations (outpatient clinics and hospitals).

Processes are unavoidable consequences of specialization. They require scheduling and coordination of different tasks and providers. As more caregivers get involved, the need for communication and coordination increases. Process management becomes particularly challenging when a patient journey crosses organizational borders, i.e. a patient is treated by several units, each with its own practices, schedules, and budgets.

2.2 Processes and capacity

The traditional thinking about production was that if everybody performs their tasks properly (quality) and keeps busy (capacity utilization), everything will turn out just fine. As production grows more complex this is no longer obvious. It can take very long time from start to finish while uncompleted cases pile up, customers are kept waiting or patients are sent home to wait for the next step.

The thing that moves to eventually become a sellable product or a completed patient case is called the flow unit. The time a flow unit spends in the system is called throughput time.

In addition to quality and capacity, time became a central management issue. Incidentally, this also required a shift from producer focus to customer focus. After all, it is the patient that must wait. Waiting time becomes a central element of patient centricity.

Every patient would love to have the full and undivided attention of a multi-skilled team offering a seamless flow of diagnostics and therapies. Unfortunately, this would be very costly, as specialists would have to stay idle waiting for their turn to make their contribution.

Management involves two basic tasks: the management of production units, such as clinics, so that capacity is utilized and quality assured; and the management of patient processes from beginning to end so that throughput time is kept at a minimum.

Capacity utilization (being busy) and throughput time (flow) may constitute a trade-off that requires optimization.

2.3 Different processes

In colloquial language, 'process' means any sequence of events. In health services 'process' means four different things.

1. A continuous process advancing in minuscule increments, such as healing of a wound or the development of a tumour, or a day-to-day struggle as in prevention and continuous care.
2. A series of tasks within a touchpoint, such as all the things that must be done in a given order for taking a blood sample. Skill means the mastery of such processes.
3. Repetition of similar tasks to a set of flow units, such as administering vaccination to a group of people. Each repetition should conform to a standard procedure (quality), and time window (capacity).

4. A *series of steps (flow)* administered to the same patient.

Processes as series of steps are the central concern of PJML.
The steps have the following characteristics:

- a beginning and an end (discrete),
- are separated in time, such as a series of scheduled appointments,
- take place at one or several workstations, which are
    - a location (clinic, ward), ambulance, or online, where
    - tools and technologies (therapy) are available
    - administered by professional service provider(s),
    - within a care relation, which includes the rights and responsibilities of a patient.
- are connected into flows through handovers.

The steps that involve patient – provider interactions are called *touchpoints*. Others may be back office tasks to which the patient is not personally participating, such as decisions, data analysis, and communication between caregivers.

2.4 Integration and coordination

If a patient has multiple problems and is treated by several actors, the need for integration arises. It means that all relevant information is considered to produce an integrated patient pathway.

Coordination means the communications and adjustments when a pathway is executed.

2.5 Handover and setup

As a patient journey proceeds, the patient is handed over from one actor to another. A *handover* carries information about what has been done, what the situation is and what needs to be done next.

In process maps handovers are depicted as arrows connecting various steps, modules and decision points.

When a handover happens, the receiving service provider needs to perform a *setup*: mentally assess the situation (*go – no-go*), use competence to confirm what should be done, and eventually make physical preparations (supplies, instruments, facilities). Assuming that service providers are competent (*can do*), and motivated (*want to do*), the handover and setup enable them to *know what to do* in a particular situation.

A great deal of the problems with patient processes can be traced back to handovers, missing or incomplete information which may lead to faulty or incomplete setups.

2.6 Setup and processing

The relation between setup and the performance of a step (*processing*) defines the basic process types.

- In a *standard* process one setup is followed by identical repetitions of steps.
- In a *routine* process there is a basic template or repertoire of actions that is negotiated and adjusted for each patient as a setup for action.
- Non-routine or *explorative* process can't be planned more than a few steps ahead. The setups involve fact finding, sense making and risk taking.

A patient journey may include all three types of processes.

PJML and pre-defined patient pathways are most applicable to routine processes. Standard processes can be managed by protocols. Explorative processes require craftmanship.

2.7 Summary

The Healthcare Operations Management view is founded on the conception of processes as sequences of steps performed by several actors with different competencies requiring integration, coordination, timing, communication and other process management methods.

[1] Vissers, J., Elkhuizen, S., and Proudlove, N., (2022) Operations management for healthcare, Taylor & Francis. Lillrank, P., (2018) The Logics of Healthcare. Taylor & Francis.

[2] The distinction between clinical and care pathways was developed within the PATHWAYS project.

3 OUR NEW CONCEPTS

While the Pathway project builds on the extant literature and accumulated knowledge, it has also introduced a few novel conceptualizations. In addition, a substantial body of formalism and a rich set of attributes have been developed around both the newly introduced and the existing core concepts

3.1 Pathways and journeys

Process management usually makes the distinction between plans (technical specifications, volume targets, etc.) and actual output. The difference is a quality problem. Similarly, in healthcare a distinction needs to be made between processes as planned, and processes as they turn out in the real world. The former are called pathways, the latter journeys.

A *patient pathway* is a plan for a service production process. It is divided into two components:

- *Clinical pathway* is a plan for clinical interventions based on diagnostics and clinical decisions,
- *Care pathway* is a plan for supporting activities, such as information, scheduling, self-care, and monitoring.

A *patient journey*, the empirical reality, consists of:

- execution of a pathway, (*what was done*), which can be expressed as a series of decisions, steps and touchpoints,
- changes in a patient's medical condition (*what happened*), and
- the activities, cognitions and emotions of a patient and significant others (*how was it experienced*).

The patient journey perspective emphasizes that meaningful things happen between touchpoints.

Pathways and journeys may end with recovery or continue as chronic or palliative care.

3.2 Patient Journey Disruptions (PJD)

The analytical distinction between clinical pathways, care pathways, and patient journeys has important implications for problem analysis and improvement.

A patient journey may turn out as planned, better, or worse. As clinical medicine is not an exact science, and there is variability in workload and resource availability, as well as in patients' circumstances, conditions and behaviours, simple plan -actual -comparisons are often not justified. Sticking strictly to a plan when situations change is not advisable.

A patient journey disruption (PJD) has three defining characteristics.

PJD is an adverse event or situation that in a way or another originates in the care pathway. Problems that originate within the clinical pathway are medical errors and needs to be treated as such within the medical community. Problems that originate in care pathways are typically related to capacity, coordination, and communication, i.e. management issues.

PJD involves agency. The origin can be traced back to somebody, caregiver, planner, patient or other stakeholder, or something, such as faulty communication routines. Therefore, realized risks, accidents and random happenstances are not included.

Since all adverse events are neither predictable nor preventable, a PJD is defined as a deviation from what could be reasonably expected in given circumstances. For example, it is reasonable to expect that lab results are delivered promptly, and that appointments are kept. It is not reasonable for a patient with mild symptoms to expect priority treatment in a crowded emergency room.

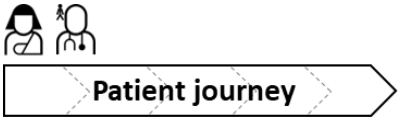
Patient journey disruption is an analytical concept that helps identify managerial problems in patient processes, and thereby enables problem solving and process improvement.

4 INTRODUCTION TO PJML

A journey is fundamentally temporal: it unfolds over time and consists of a sequence of steps. This gives it a process-like character, regardless of context or domain. A journey always takes the perspective of an end user and describes what happens, in what order, and through which steps the individual moves from one stage to the next when interacting with one or more service providers. In practice, however, a patient journey typically involves many actors and can extend over a long period of time, sometimes years. This distinguishes patient journeys from most customer journeys and user journeys, which are often shorter in duration and involve fewer actors. Two elements define the structure of any journey. **Actors** represent the people, organizations, or systems involved. **Touchpoints** capture the moments of interaction between the individual and these actors.

3.3 Touchpoints are the steps of a journey

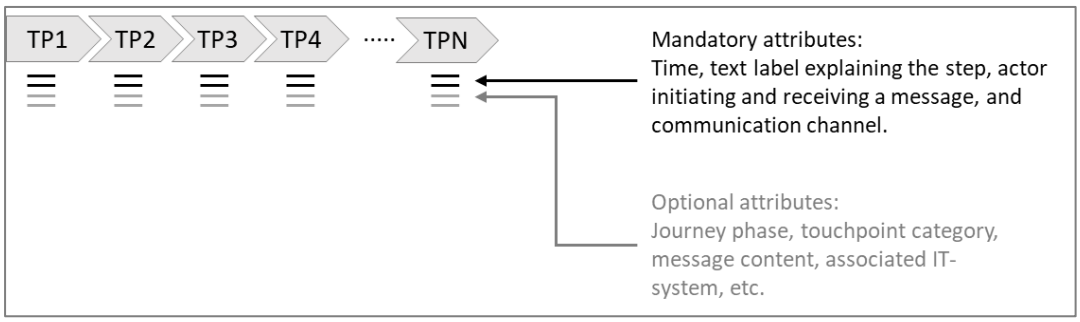
Actors and touchpoints are the basic ingredients of a patient journey. In its simplest form, a patient journey consists of at least two actors, one of whom is the patient — for example, a patient and a general practitioner. It also consists of a chronological sequence of touchpoints and must include at least two touchpoints to constitute a journey. In practice, however, a patient journey may involve dozens or even hundreds of touchpoints over time, depending on its duration and complexity.



A patient journey can be understood from two complementary perspectives: the **planned journey** and the **actual journey**. The planned journey represents the intended patient pathway[1], describing how care is designed to proceed according to guidelines, organizational routines, and care plans. The actual journey, in contrast, reflects what truly happens over time — including deviations, adjustments, delays, and individual adaptations. In addition to the observable course of events, the actual journey also includes the subjective, cognitive, and emotional dimensions commonly referred to as patient experience.

Think of the patient pathway as the blueprint, that is, the designed and intended sequence of events. The actual journey is the execution of that pathway, as it unfolds over time and is experienced by the patient, generating process events and data. Comparing the pathway and the actual journey makes it possible to identify differences between intention and reality, and explore opportunities for coordination and improvement.

Each touchpoint in a journey is associated with a number of properties or attributes. Some of these are so fundamental that they are mandatory. In addition, there are several other attributes that may be used for various purposes, as shown in the figure below. The touchpoints must have a timestamp or at least there must be a sequence of occurrences. A text label is also mandatory, explain the content of the step. For communicative events there must also be a sender and a receiver of each step, which also means there must be a communication channel like face-to-face or web interaction. A touchpoint is formally defined in the class diagram and further explained in the documentation.

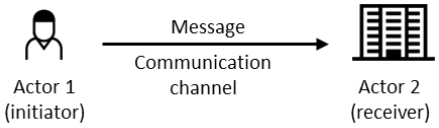


Touchpoint and all the other elements are formally defined in class diagrams and further described in the current CJML documentation[2]. Most touchpoints involve communication and are defined as

[1] We use the term pathway instead of planned journey, to clearly distinguish it from the actual journey.

[2] https://cjml.no/cjml/

instances of communication or interaction between two actors. Actions, in contrast, are touchpoints that do not involve communication, for example a patient taking medication. A communicating touchpoint is defined as an instance of communication or interaction between two actors. They can be represented by a simple communication model consisting of a sender, a receiver, and a message transmitted between them through a communication channel. Touchpoints are the primary flow elements in PJML diagrams. The *message* itself, however, such as the content of a conversation or an email, is not part of the diagram. As shown in later diagram examples, communicating touchpoints include both sender and receiver, as well as the communication channel.



3.4 Actor

Actor is a central concept in PJML, representing the entities with which the patient interacts. A patient journey must include at least one actor in addition to the patient. In practice, however, journeys typically involve many different actors over time, with a wide range of roles, functions, and areas of specialization. Actors are not limited to people or physical entities such as hospitals; they may also include digital systems, such as health portals, or AI agents, as long as they interact with the patient. Actors are represented by graphical symbols, with multiple variants available for each actor type.

Based on empirical studies, we developed a patient-centered classification of actors grounded in those reported and experienced by patients. Table 1 presents this classification. It extends beyond healthcare providers to include health portals, welfare services, payment systems, employers, and other relevant actors involved in the journey. The categories describe different types of entities that may interact with the patient or influence the journey, covering both clinical and non-clinical actors as well as digital and public services.

Actor category	Hint	Definition
Patient's personal network	People close to the patient	The private sphere of the patient, such as family members, friends, or informal caregivers.
Healthcare provider	Delivers care	Entities delivering medical treatment and care, e.g. hospitals, general practitioners, and physiotherapists.
Clinical support service	Supports clinical care	Services that support healthcare providers, such as laboratory testing, diagnostic imaging, or pathology.
Digital health system	Health-specific digital tools	Digital tools designed to support patients and healthcare providers, e.g. patient portals and clinical systems.
Digital system – general	Generic digital infrastructure	Platforms serving the general population for public services or utilities, e.g. digital postboxes and payment solutions.
Patient organization and auxiliary service	Advice and practical support	Organizations and services offering advocacy, guidance, or practical support, e.g. patient organizations or transport services.
Employer	Workplace	The patient's employer or workplace, relevant for sick leave, accommodations, or return to work.
Welfare service and social care	Social and welfare support	Public or private services supporting social, financial, or daily living needs, e.g. sick leave benefits or home care.
Health authority	Governs healthcare	Entities responsible for regulation, planning, and governance of healthcare at national or municipal levels.
Health registry and quality system	Collects health data	National or regional systems collecting and analyzing health-related data to support quality improvement and oversight.
Other	Anything else	Any additional actor intersecting the patient journey that does not fit the above categories.

Table 1 A patient-centred classification of actors involved in patient journeys

The actor classification outlines the types of actors patients may encounter in a journey. To support consistent modelling, we now turn to how actors are formally represented in PJML, see Figure 1. Patients often report actors at different levels of detail, ranging from broad categories such as "hospital" to specific roles like "physiotherapist in the neurology department." This highlights the

need for flexible levels of abstraction. The Actor class has three subtypes: EndUser, ServiceProvider, and External. Here we focus on the ServiceProvider. The ServiceProvider class is extended with a serviceProviderType attribute to capture the main categories of actors identified by patients. These categories are defined in the SPTypes enumeration. Additional attributes are included to record information such as legal name, address, physical location, and interactions with healthcare personnel and their roles. The HealthcareRole class is used to represent roles (e.g., nurse, physician, surgeon) and their descriptions. Informal and formal names reported by patients can be captured using the existing Actor.name and ServiceProvider.providerName attributes.

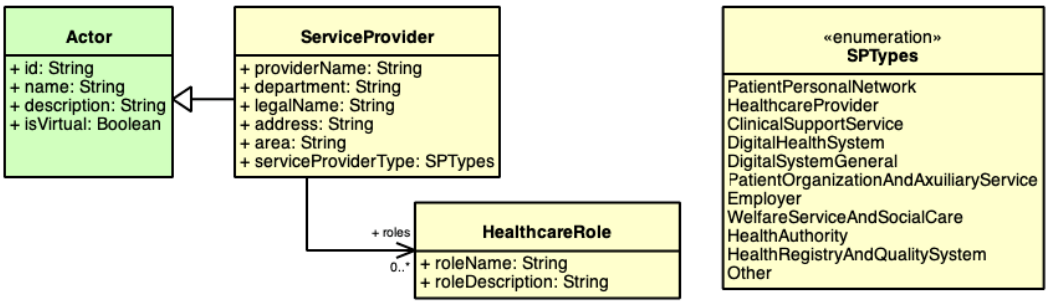


Figure 1 Extending the Actor formalism with categories of healthcare actors

3.5 Diagrams in PJML

The journey network diagram, or swimlane diagram, is well suited for modelling patient pathways and journeys, as these typically involve multiple actors. An illustrative case is a patient who visits a general practitioner (GP) due to pain and is referred to a specialist. The diagram in Figure 2 shows a simplified representation of this patient journey. The actors involved are the patient, the GP, and a specialist, where the GP and the specialist are each represented by their own horizontal swimlane, alongside a separate swimlane used for comments and notes. Communicating touchpoints are shown across these lanes, with each interaction having both a sender and a receiver in the respective swimlanes.

The journey begins when the patient experiences pain and books an appointment with the GP. During the consultation, the GP examines the patient and concludes that a specialist assessment is needed. An electronic referral is then sent to the specialist clinic. The clinic receives and assesses the referral and decides to call in the patient. An appointment is scheduled, and the patient receives information about the appointment, followed by an SMS reminder closer to the date. The journey continues with the specialist consultation at the outpatient clinic, where the patient is examined and a decision is made regarding further treatment, such as surgery. Each touchpoint captures the interaction between actors, including both the sending and receiving side of the communication.

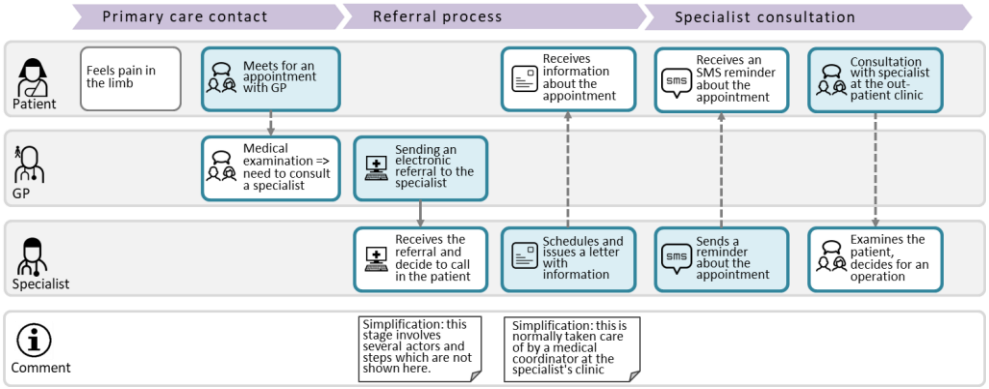


Figure 2 Example diagram of a patient being referred to a specialist.

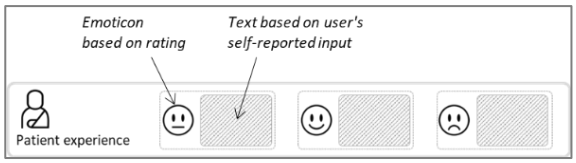
The example diagram is, of course, a simplification. Multiple data systems are involved, for example in sending reminders to the patient, and aspects such as co-payment are not shown. The comments

swimlane can be used to document such limitations, assumptions, or additional contextual details. Note that the example includes an *internal handover* from the GP to the specialist as part of the referral process. This handover is not visible in the patient's swimlane and only becomes apparent when the specialist contacts the patient. As noted earlier, PJML includes only elements that directly involve the patient. The handover is therefore represented because it leads to a subsequent interaction with the patient, where the specialist enters the journey.

3.6 Patient experience

Patient experience (PX) is commonly measured at specific points in time and often retrospectively, for example through patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs). These approaches typically capture isolated snapshots rather than the experience as it unfolds across the full patient journey.

PJML incorporates principles from human–computer interaction (HCI) research when representing human experience. Here, experience is understood as a complex and multifaceted phenomenon that is subjective, dynamic, and context dependent. Therefore, it is associated with actual journeys rather than planned pathways. It is based on the patient's own self-reported input; otherwise, it should be explicitly marked as anticipated experience. In line with this perspective, experience cannot be assigned to a journey at a general level, as it is inherently individual. PJML therefore captures PX at the level of the individual patient journey. In swimlane diagrams, PX is represented in a dedicated swimlane and linked to specific touchpoints.



In practical terms, PX is captured over time through a structured longitudinal approach. Patients are first recruited and interviewed to establish the context of the journey. The patient then completes a structured diary, documenting experiences as they occur. Finally, a debrief interview is conducted to review the diary entries and reflect on the journey as a whole. This approach makes it possible to link experiences to specific touchpoints and understand how they evolve over time.

As part of our empirical work with patients and next-of-kin, we used the critical incident technique[3]to study positive and negative patient experiences throughout patient journeys. Patient-reported experiences were analyzed to identify critical incidents across the patient journey. Content analysis of the data resulted in a categorization of patient experiences (Table 2), capturing key themes in communication, information, and coordination.

Category of critical patient experience	Meaning
Access to information	The patient has access to information when desired
Timely information	The information is available for the patient at the right time
Information quality	The information is understandable
Informed healthcare workers	Healthcare workers are informed about the patient's situation
Clinical empathy	Healthcare workers have empathy when interacting with the patient
Patient and next-of-kin involvement	Services apply a patient-centered approach. Services involve next-of-kin
Communication and information exchange within the healthcare system	Communication and information exchange within and across healthcare providers is satisfactory
Coordination	Services are experienced as coordinated across healthcare actors
Planned services	The service is predictable
Time and tempo	The service is given in a speedy manner
Access and availability to services	Services exist and have capacity to help the patient
One contact point	Services provide patients with one contact point

Table 2 Categories of critical patient experiences identified from content analysis

[3] Halvorsrud, R., Melby, L., Gjermestad, K., Bogale, B., & Solem, I. K. L. (2025). "I Became the Messenger Between the Hospitals": A Study on the Journeys of People With Cancer Using the Critical Incident Technique. Health Expectations, 28(2), e70211.

3.7 Categorization of touchpoints

Patient pathways are often long and complex. They include everything from key clinical events, such as consultation with a specialist, to interactions of a very different nature, such as an SMS reminder or a link to a payment solution. To capture this variation, PJML allows touchpoints to be categorized. Table 3 presents a classification of touchpoint types developed for this purpose. The categories are defined from the end-user perspective and describe the function of each interaction rather than the channel, actor, or domain. Together, they provide consistent vocabulary for analyzing, comparing, and modelling journeys.

Category	Hint	Definition	Example from healthcare
Clinical encounter	The main thing	The primary service interaction where value is created. Can occur repeatedly (patient journey) or as a single stage in a journey (online shopping).	Medical consultation or examination with HCP for the purpose of diagnosis, treatment or follow-up
Supportive encounter & handover	Supporting activity or transfer of responsibility	Action carried out as part of delivering or enabling the core service. Can also be a task or responsibility handed over from one service providing actor to another (who in turn contacts the end user)	A GP sends a referral to a specialist, or a patient is transferred from one department to another for further treatment.
Confirmation	Something is confirmed	Verification that an action, booking, or message has been received or accepted.	An appointment with a GP has been booked
Status update	Something has changed in an ongoing process	Information about a change in state in an ongoing process. process progression after confirmation	If test results is done regularly, like a process, like in cancer screening, it belongs here and not under clinical encounter
Notification	Something is available (elsewhere)	A message indicating that new information is available elsewhere. Points to information without including its content	Lab results are available (elsewhere)
Reminder	Don't forget	A prompt to remember something already agreed. Contains no new information	Reminder for appointment or medication
Inquiry	A question is asked	An interaction initiated to clarify uncertainty or request information. Someone asks because they lack understanding. No new process state is asserted.	Patient asks doctor "can I take this medication together with food?".
Instruction	"you must" or "you should"	An interaction in which one actor directs another actor to perform a specific action in order to proceed in the service or comply with requirements	Please fast 3 hours before the surgery
Authentication & authorization	"prove who you are"	Digital or physical verification of identity or presence (e.g. BankID login, check-in)	check-in at clinic or registration in waiting room
Payment or financial interaction	“you pay or are charged”	Exchange of information or action related to cost, coverage, or refund.	The patient pays a co-payment at the clinic or receives a receipt or invoice for the consultation.
Other	Doesn’t fit the above	Everything else	

Table 3 Generic touchpoint categories

3.8 Phases of the patient pathway

PJML supports structuring content according to the phases of a patient pathway, making it possible to describe how patients move through different stages of care. The phases of a patient pathway vary depending on the situation, for example, whether the pathway concerns an injury, an acute illness, or a chronic condition. Some phases are iterative, meaning that patients may move back and forth between them several times as their condition and needs change.

The following generic phases can be used to describe a typical disease course:

- Symptom phase: the patient experiences early signs or concerns.
- Assessment and diagnosis: clinical evaluation, testing, and diagnostic clarification.
- Initiation of treatment: first treatment decisions and start of interventions.
- Treatment: active therapeutic phase, which may include multiple modalities.
- Follow-up and monitoring: ongoing evaluation of progress, side effects, and adjustments.
- Rehabilitation and self-management: recovery, functional improvement, and patient-led strategies.
- Long-term follow-up / chronic phase: management of long-term conditions or stable chronic disease.
- Palliative phase: care focused on quality of life, symptom relief, and support.

4 TEMPLATES, GUIDANCE, AND CASE STUDIES

The Pathway Toolbox provides a range of practical resources to support the modelling and analysis of patient pathways and journeys. These include downloadable templates, case studies from real patient journeys, and step-by-step guidance on data collection and analysis. Together, these resources are designed to help researchers, healthcare professionals, and practitioners apply PJML in practice and develop a deeper understanding of patient-centered care processes.

4.1 Templates

The toolbox includes a set of PowerPoint templates designed to support the creation of patient pathway and patient journey diagrams. The templates provides flexible layouts that can be adapted to different cases and levels of detail, see Figure 3.

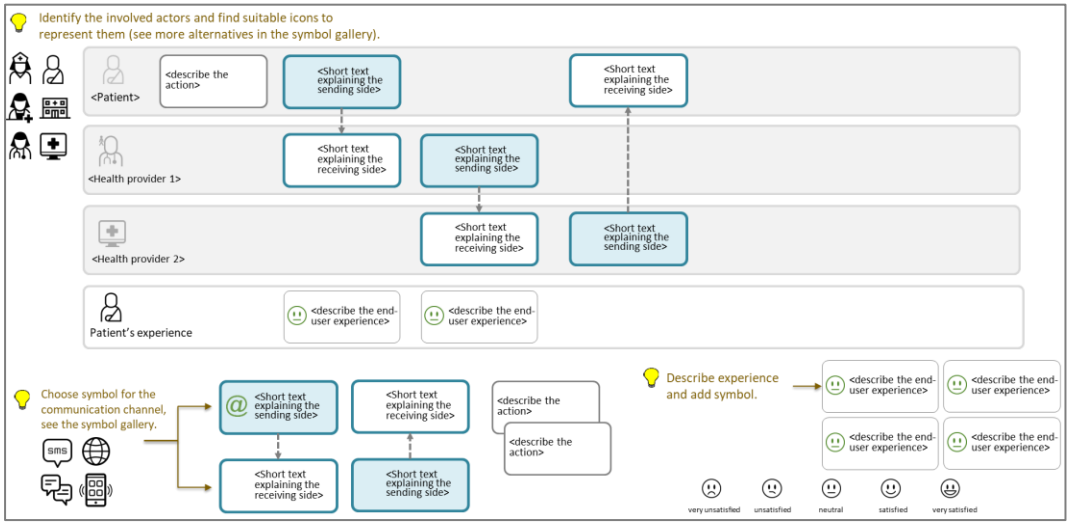


Figure 3 Example of a template for patient journey diagrams

The templates also include a gallery of healthcare symbols (Figure 4) covering actors, communication channels, and elements such as patient experience. In addition, the template contains example diagrams that illustrate how the elements can be combined in practice.

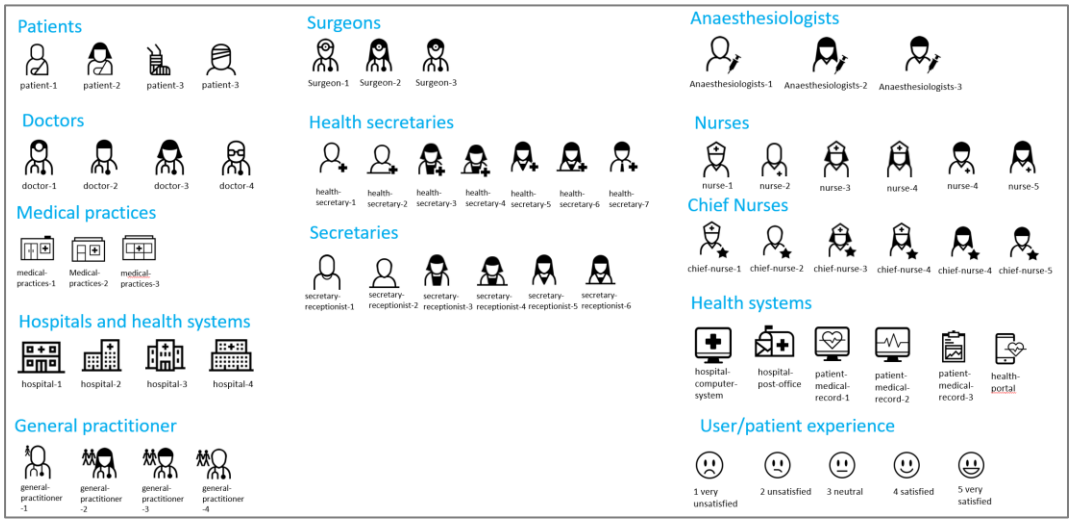


Figure 4 Healthcare symbols

4.2 Methods and practical guidance

The toolbox provides practice-oriented methods and guidance for analysing and modelling patient pathways and journeys. These resources support the full process, from data collection to analysis and interpretation, and are grounded in empirical studies of patient journeys and experiences. Together, they offer practical support for understanding how care unfolds from the patient's perspective and for identifying challenges in coordination and information flow.

Examples of methods and tools in the toolbox include:

- Patient journey analysis
- Iterative modeling of patient pathways
- Patient journey disruptions analysis
- Critical incident technique
- Survey methods
- Expert evaluation
- Interview guides

4.3 Case studies

The toolbox includes a set of case studies drawn from real clinical settings, illustrating how patient pathways and journeys can be analyzed and modelled in practice. The cases cover different conditions and contexts, including kidney cancer and multiple sclerosis, and demonstrate the use of various methods presented in the toolbox. Together, they provide concrete examples of how to apply concepts, methods, and modelling techniques in real-world situations.

Examples of case studies in the toolbox include:

- Mapping of patient journeys
- Patient pathways in specialist care
- Pathway modelling with expert evaluation
- Pathway analysis using digital care data
- Cross-disease survey of patient pathways
- Critical incident study of patient experiences
- Longitudinal patient journeys
- Transitions between levels of care
- Rehabilitation pathways
- Clinician perspectives on coordination

5 EVALUATION

Evaluation is essential to understand whether CJML works in practice and creates value. Throughout the project, the content has been continuously shared and presented to healthcare professionals and other stakeholders. The toolbox has also been promoted and discussed at national and international conferences, seminars, and workshops. In this chapter, we present two major evaluations and what we learned from them.

5.1 Evaluation at Oslo University Hospital

A feasibility evaluation was conducted to assess PJML in a real healthcare setting. Here, we summarize the main findings. The full study is described in detail in a separate publication[4].

We interviewed four urologists, one cancer coordinator, and one patient coordinator. Participants were asked to review and reflect on diagrams of the patient pathway and the patient journey, which they could study both before and during the interview. We asked about participants' first impressions, ease of understanding, perceived usefulness, potential use of such visualizations in practice, and whether any important information was missing.

Most participants reported that they do not use diagrams in their daily work, and visual pathway representations are generally not common in hospital settings. Despite limited prior experience, the diagrams were largely seen as intuitive and easy to understand. On a scale from 1 to 5, most participants rated ease of use as 4 or 5. One participant rated it 2, noting that the diagrams contained too many boxes and too much information.

When it came to usefulness, participants did not see strong value for their own day-to-day clinical work. Experienced clinicians already know the key steps in the pathway and focus mainly on the parts they are responsible for. However, they highlighted clear potential value at an organizational level. They pointed to possible benefits such as:

- Creating shared understanding across roles
- Identifying bottlenecks and inefficiencies
- Supporting coordination and improvement efforts
- Communicating with managers or health authorities
- Training new staff and use in education

Several emphasized that usefulness depends on context, purpose, and audience. What may not be helpful in daily clinical routines could be very useful in quality improvement work, management discussions, or teaching.

Participants were mostly skeptical about showing detailed diagrams to patients, as they could feel overwhelming and create confusion if the actual journey differs from the visualization. Some suggested that very simplified diagrams with only key touchpoints might be more appropriate for patient communication.

Overall, the evaluation showed that the visualizations are easy to understand, but their value depends strongly on how and where they are used. Table 4 provides an overview of how visualizations of patient pathways and patient journeys can be used.

Organizational/Managerial	Instructional	Communicative
Map practices across roles and departments	Training of new employees	Communicate efficiency potentials to hospital managers
Create shared understanding	Use in educational settings	Communicate with health authorities
Identify bottlenecks and improve efficiency		Communicate with healthcare professionals

[4] Larsen, A. G., Halvorsrud, R., Berg, R. E., & Vesinurm, M. (2024, May). Dual-Perspective Modeling of Patient Pathways: A Case Study on Kidney Cancer. In Nordic Conference on Digital Health and Wireless Solutions (pp. 51-68). Cham: Springer Nature Switzerland.

Support coordination and improvement efforts		
Contribute to standardization and equal treatment of patients		

Table 4 Areas of use for visualization of pathways

5.2 Evaluation at Helsinki University Hospital

A development and evaluation exercise in the context of kidney cancer was conducted at Helsinki University Hospital. Oncologists, oncology nurses and patients were interviewed. For details, see Essi Miettinen: Modelling Complex Patient Processes in a Multi-Producer Environment (MS thesis, Aalto University 2025). Participants evaluated the tool using the structured framework depicted in Table 5.

Evaluated dimension	Questions guiding the evaluation
Accuracy	Does the proposed extension enable more precise or correct representation of processes?
Clarity	Does this enhance or reduce 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 or a niche case? Is it easy and intuitive for modelers and stakeholders to adopt and use?
Completeness	Does it help model the relevant aspects that are currently missing and identified in this study?

Table 5 Evaluation framework

The study identified several specific areas where the notation required further development to accurately model the intricacies of the kidney cancer care pathway, see Table 6.

Proposed improvement	Proposed, added value	Expert validation
Decision point	Enables clear visualization of decision points and branching paths in journey network diagram.	Made decision should be underlined before the decision point, inclusive cases bring value to the decision event.
Temporary, non-linear timeline	Allows simplified process model for alternative care paths.	Breaking the timeline will make the process visualization more complex and confusing.
Looping mechanism	Supports representation of iterative actions and repeated behaviors within a process	Clarity needs further testing on more cases but overall, the usability of the improvement is high.
Angled connectors	Enables clear and accurate depiction of the process flow, even in complex cases.	If the use is connected to the non-linear timeline, the improvement isn't improving the clarity. Otherwise, no opinions for or against.
Modularity	Encourages structured and reusable modelling,	Noted supporting all aspects of evaluated dimensions, essential for clear process picture that is yet allowing the sufficient share of information.

Sub-processes at the process level	Enables detailed breakdown of complex stages while maintaining a clear overview.	The usability of sub-processes is high, and it enhances the clarity and greatly. Requires the definition for the use: what is the broadest and most precise degree of detail included and for which user.
Call-activity	Facilitates reuse of standardized processes by referencing external process logic.	Requires the process presentation as modules. Might cause confusion from the patient's viewpoint, visualization cannot seem like going backwards.
Data object	Provides a way to visualize and track uploaded and retrieved data within process steps.	Visualization of prerequisite information adds clarity to the decisions. Partial support for a combination of the data object and EHR in a separate swim lane. Indicating upload and retrieval of data is relevant for the patient view but showcasing all data use is not.
Discussion point	Enables a visual representation of a shared interaction point to capture the collaborative nature in patient-centered care.	High usability, clarity and accuracy as it provides more realistic representation of interaction. Completeness of the visualization is considered high but guidelines for the use are required.

Table 6 The evaluated improvement proposals

This study demonstrates that while the CJML offers a strong foundation for patient-centric design, it requires specific structural enhancements to effectively model the complexity of modern healthcare systems. By developing and validating extensions, it is possible to bridge the gap between the operational requirements and patient-centricity. These artefacts help move CJML from a purely descriptive visualization tool into a functional instrument for care planning, capable of identifying bottlenecks, mapping data flows, and formalizing the critical role of value co-creation.

6 SUMMARY OF THE PATHWAY PROJECT

Patient pathways are essential for organizing modern healthcare, yet they are often poorly defined and described in fragmented ways. Healthcare systems are becoming increasingly complex due to specialization, digitization, and longer life expectancy. Patients frequently interact with multiple providers across organizations and sectors, making coordination and communication difficult. At the same time, there are few systematic methods for describing, analyzing, and communicating patient pathways. The Pathway project addressed these challenges by developing a theoretical foundation and extending a visual modeling language for patient pathways. Led by SINTEF Digital, in collaboration with the University of Oslo and Aalto University in Finland, the project aimed to provide a robust framework for structuring, specifying, and communicating complex patient pathways.

The project was grounded in a patient-centric approach. Patients and patient organizations were actively involved throughout the work, focusing on two distinct groups: people living with multiple sclerosis (MS) and those diagnosed with kidney cancer. Using these as primary cases made it possible to explore variations between chronic, lifelong care and the more intensive diagnostic and treatment phases typical of cancer pathways, thereby strengthening the robustness of the tools.

A scoping review of the literature on patient pathways revealed a fragmented field, with various modeling languages used at different levels of detail. Against this background, we highlight the need for a patient-centered visual modeling language capable of distinguishing the planned (static) pathway from the real, individual patient journey. A subsequent survey of healthcare professionals showed that although more than 90% relied on patient pathways for structure, they still encountered substantial obstacles, including outdated information and rigid systems.

Methodology has been developed for patient-centric studies and for longitudinal exploration of patient experience across extended care processes unfolding over several months. Drawing on empirical insights from patient journey case studies, a new formalism for patient journeys has been created, including a structured approach to classifying and abstracting the actors involved in a journey, as well as categorizing different types of interactions (touchpoints). By using workshops, interviews, and diary studies, we mapped individual patient journeys and compared them with planned patient pathways. This led to the introduction of the concept of "patient journey disruptions", understood as deviations from the intended and reasonably expected journey that often create barriers to integrated care. Workshops and interviews with cancer patients and their next-of-kin, using the critical incident technique, revealed key moments in their care experiences. Positive incidents were typically associated with timely information and well-coordinated care. In contrast, nearly 40% of negative experiences were linked to fragmented services. In these situations, patients often had to act as informal messengers between hospital departments and providers because of breakdowns in information flow. This points to a persistent lack of progress in service integration.

The primary result of the project is a comprehensive toolbox. Although the research was grounded in cases of cancer and MS, the toolbox is designed as a general resource applicable across diagnoses. It includes structured methods, practical templates, step-by-step guidance, illustrative case examples, and a handbook that clarifies key concepts such as patient pathways, patient journeys, patient experience, and patient journey disruptions. The toolbox is intended for clinicians, coordinators, technologists, researchers, and others involved in healthcare services. It supports the description and visualization of planned pathways, the documentation and analysis of patient journeys, and the identification of coordination challenges and opportunities for improvement. All resources are publicly available at https://cjml.no/health/.

The results contribute to a conceptual foundation and practical tools for understanding and improving patient pathways. The project has also resulted in the completion of a PhD and a substantial scientific output within health services research and related fields, with results presented at major international conferences. By making both the concepts and resources openly available, the project supports broader use of patient-centric approaches to analyzing, communicating, and improving healthcare services.