

**Exploring the Intersection of Service-Dominant Logic and Patient Pathways:
the Healthcare Value Dynamics Framework**

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Abstract

Purpose – This study delves into the ramifications of assimilating a marketing perspective to enrich healthcare management and communication strategies and practices along the continuum of care. Through the amalgamation of the foundational tenets of Service-Dominant Logic and patient pathways, this research endeavors to unearth nuanced insights that have the potential to elevate service provisions and stimulate holistic transformations.

Methodology – Employing an explorative approach, this research harnesses the power of longitudinal engagement with patients and conducts in-depth interviews with healthcare professionals. The application of triangulation serves to fortify the edifice of internal validity and reliability, thus ensuring the robustness and resilience of the empirical findings.

Results – The application of the systemic perspective has brought to the fore hitherto unexplored dimensions within the domains of healthcare management and communication, closing the chasm between actual patient journeys and predefined patient pathways. These dimensions encapsulate value-in-healthcare-context, healthcare co-creation, aggregation levels, shared institutionalized language, institutionalized responsibilities, and actor-to-actor interactions.

Conclusion – This undertaking culminates in the conceptualization of the Healthcare Value Dynamics Framework. Forged through the dynamic interplay between theoretical discourse and empirically substantiated revelations, it not only redefines the parameters of value co-creation within the healthcare context but also heralds the emergence of an operational logic shift.

Limitations – Notable limitations stem from attrition in the longitudinal study and the challenges of achieving representativeness through the utilitarian yet non-exhaustive convenience sampling strategy. While the proposed framework unveils a promising avenue for further research, it remains a conceptual model, and its practical implementation may pose challenges within complex real-world healthcare environments.

Value – This erudite research contributes to the ever-evolving discourse surrounding the systemic perspective by demonstrating its applicability within the labyrinthine ecosystem of healthcare. It establishes a sturdy foundation for the perpetual advancement of Service-Dominant Logic.

Keywords – Service-Dominant Logic, Systemic Perspective, Service Eco-Systems, Value Co-Creation, User journeys, Healthcare, Patient Pathways.

Preface

My heartfelt gratitude extends to all those who have played pivotal roles in this undertaking. This journey has entailed not only rigorous research but also the invaluable insights shared by healthcare professionals and patients who generously imparted their experiences. Your contributions have been instrumental in shaping this master's thesis, a testament to your unwavering commitment to advancing healthcare management and communication.

As you navigate through this framework and contemplate its theoretical implications, please remember that it serves not as a final destination but as a catalyst for change in the realm of healthcare. It stands as proof of the potential inherent in collective wisdom and human resilience when confronted with evolving healthcare challenges. May it serve as inspiration for further innovation and collaboration in the tireless pursuit of enhanced healthcare for all.

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To my unwavering pillar of strength, Johan K. Finnøy, our journey remains an ongoing and shared endeavor.

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1.0 Introduction

The Norwegian healthcare system is recognized for its universal coverage, contributing to the overall well-being of the national population, characterized by a relatively high average life expectancy (Norwegian Institute of Public Health, 2018). Nevertheless, akin to healthcare systems worldwide, the Norwegian system confronts a spectrum of challenges that imperil its capacity to provide optimal patient care. An impending transformation looms large as the progressively aging population and reduced population growth, attributed to declining immigration and fertility rates, set in motion a chain reaction influencing the scope of government activities across all administrative levels and sectors (Statistics Norway, 2020). As per population projections by Statistics Norway (2020), it is anticipated that Norway will, in the coming decade, experience an unprecedented demographic shift, with a greater number of elderly citizens surpassing the count of children and adolescents for the first time in its history.

Recognizing the evolving dynamics within the healthcare industry, there is a compelling impetus for a collaborative effort between scholars and practitioners to devise strategies aimed at enhancing care coordination, bolstering communication, and ultimately contributing to the sustainable provision of healthcare services. As part of the ongoing transformation in the Norwegian healthcare landscape, a myriad of promising and noble prospects unfurls. These encompass cutting-edge advancements like multi-omics, telehealth, artificial intelligence, and machine learning, all of which serve to streamline healthcare operations and augment access to health data (Collins, 2023). Concurrently, the concept of patient pathways has been steadily gaining prominence in both the healthcare sector and life sciences. This ascendancy is driven by the profound understanding that well-orchestrated and seamless patient pathways are of paramount importance in furnishing high-quality care and optimizing patient outcomes. Moreover, this wave of enthusiasm and consolidation is deeply rooted in the recognition that these pathways significantly contribute to social sustainability on a broader societal scale.

In broad terms, the notion of patient pathways encompasses the sequence of procedures and interactions patients undergo when availing healthcare services, commencing from their initial engagement with the healthcare system and culminating in the clinical outcome of their care (Schrijvers et al., 2012). Nonetheless, this concept introduces complexities engendered by the conspicuous absence of lucid and standardized definitions (Halvorsrud & Skjuve, 2018). The prevailing literature frequently employs a medley of terms (e.g., patient flow, clinical pathways, integrated pathways, critical pathways, care pathways, care maps, and patient journeys) interchangeably, leading to confusion and ambiguity (Allen, 2009; Vanhaecht et al., 2012). A preliminary research initiative conducted in 2018 illuminated this quandary, shedding light on the disparities in the interpretation of terminology and the heterogeneous practices that prevail both within and among healthcare institutions (Halvorsrud & Skjuve, 2018).

While differences in terminology, levels of abstraction, and symbolic representations abound, an underlying commonality threads through pathway definitions – a distinct emphasis on the chronological sequence of a patient's interactions within the public health infrastructure (Halvorsrud & Skjuve, 2018). This shared attribute prompts consideration of a conceptual nexus between patient pathways and user or customer journeys, concepts rooted in the domains of service design and research. Exploring this linkage promises to yield insights from interdisciplinary depths, affording the adoption of efficacious strategies and frameworks aimed at enhancing the management of pathological conditions. Consequently, it becomes a compelling imperative to circumnavigate the intricacies surrounding pathways, harmonize terminology, and harness pertinent concepts derived from empirical and theoretical service research, thereby elevating our comprehension of seamless communication and the facilitation of service provision.

In the context of this proposed research, the theoretical underpinning of Service-Dominant Logic (SDL) facilitates a profound comprehension of the intricate interdependencies among actors within the healthcare domain. Lusch and Vargo (2014, p. 160) elucidate a systems perspective as "*a relatively self-contained, self-adjusting system of resource integrating actors that are connected by shared institutional logics and mutual value creation through service exchange*". This view underscores the collaborative nature of healthcare delivery, where these actors collaborate to generate value and integrate resources. When incorporating a user journey into the analytical framework of SDL, it is essential to acknowledge that healthcare actors do not function in isolation but rather form intricate networks involving a multitude of actors (e.g., patients, their next-of-kin, hospitals, and medical practitioners). Emphasizing the significance of user engagement underscores that patients are not passive recipients of services (Norwegian Ministry of Health and Care Services, 2019). In essence, patients commonly assume an active role in their own care (Findsrud et al., 2018; Loebler, 2013).

In the specified research context, the utilization of a system-wide perspective finds justification in the potential interrelationships and synergies between the concepts delineated in patient pathway practices and the overarching tenets of SDL. This study endeavors to forge a cohesive framework through scrutiny, comparison, and discussion of these concepts. The overarching goal of this effort is to acknowledge the significance of value generation, cooperative efforts, and the holistic grasp of the healthcare ecosystem. By aligning the terminologies and phenomena drawn from both bodies of literature, this research's theoretical contribution seeks to promote the establishment of a shared lexicon and mutual comprehension. This, in turn, equips healthcare professionals and scholars with the means to partake in efficacious management and communication, with the ultimate aim of enhancing the service provision.

1.1 Problem statement

The aim in the pilot stages of the research process was to identify and define the precise research problem and its corresponding inquiries. The systemic logic harbored the potential to fortify healthcare management and communication by offering a conceptual lens that facilitates a transformative shift. This shift facilitates “*a move from a product offering to the cocreation of service(s) and experiences, from price to the cocreation of value propositions, from promotion to the cocreation of conversation and dialogue, and from a channel of distribution to the cocreation of value processes and A2A networks*” (Lusch & Vargo, 2014, p. 90). Consequently, the overarching research inquiry was precisely formulated as follow:

"How can an expanded viewpoint foster the delivery of healthcare services that are both of high quality and efficiency?"

This problem formulation focuses on exploring the impact of a broader perspective on enhancing the quality and efficiency of healthcare services. More precisely, it seeks to explore how the integration of the systemic perspective within the framework of service-dominant logic can lead to improvements in healthcare management. This research intends to dissect the mechanisms, strategies, and approaches that organizations can employ to optimize resource allocation, streamline processes, and improve coordination within the broader healthcare infrastructure. Under the aegis of the literature review, two sub-research questions arise out of the main research question:

RQ1: *“What are the key principles and concepts of the systemic perspective that can be applied to enhance the management of healthcare delivery?”*

The first inquiry seeks to identify and scrutinize the core principles and concepts stemming from SDL that offer the capacity to elevate healthcare management. The examination involves the effective integration of systemic principles into the practices and processes of healthcare organizations. Here, healthcare management pertains to the administrative components encompassing policies, standards, and guidelines, while healthcare communication pertains to the exchange of information and interactions among diverse actors operating within the healthcare landscape.

RQ2: *“How can the systemic perspective influence communication strategies and practices along the continuum of care?”*

The second research question is centered on the exploration of how the systemic perspective impacts communication strategies and practices within healthcare. It delves into the systemic perspective's role in enhancing the efficacy of communication among providers, patients, and other individuals involved in service provision. Addressing these two research inquiries enables the acquisition of a comprehensive understanding of how service-dominant logic can contribute to the improved management and communication in the delivery of high-quality and efficient healthcare services.

1.2 Positioning

While SDL scholars share a fundamental belief in the paradigm shift from a Goods-Dominant Logic (GDL) towards a service-dominant logic, they interpret the logic in marginally contrary manners, and put emphasis on different propositions and subject matters, for instance sustainable tourism or actor engagement (Alexander et al., 2018; Brodie et al., 2019; Font et al., 2021; Rather et al., 2019). While Jaakkola et al. (2015) and Aarikka-Stenroos and Jaakkola (2012) equate dyadic dimensions with systemic ones, considering the specific context chosen for this research, a deliberate decision has been made to adhere to the widely accepted service ecosystems perspective (Lusch & Vargo, 2014). The Nordic School, although not omitted from the literature review, distinguishes itself by attributing distinct connotations to SDL-related terms. For instance, Grönroos and Voima (2013, p. 9) criticizes the widely held understanding of value co-creation by contemplating that: “*co-creation can take place only through direct interactions*” (Vargo & Lusch, 2016). A distinguishment is made between direct and indirect interactions. In their conceptual apparatus co-creation only incorporates the direct contact between actors (Grönroos & Voima, 2013). To the extent that actors meet beyond face-to-face, the term *co-production* is used by Grönroos and Voima (2013) which confusingly Vargo and Lusch (2004) also refer to, but more in the sense of zooming in to a narrow position and practice a dyadic orientation (Vargo & Lusch, 2016).

The infusion of service thinking and service design concepts into the healthcare sector has yielded favorable outcomes for both patients and healthcare professionals (Ponsignon et al., 2018; Williams & Radnor, 2022). More than a decade ago Edvardsson et al. (2011) suggested that researchers should seek to study service exchange and value co-creation in the sector. Similarly, Williams and Radnor (2022) summons service science scholars to develop or test theories within healthcare. When it comes down to patient pathways in particular, the course has steered towards operations management science in favor of SDL. Health operations management (OM) academics to a large extent agree on the idea that lean management principles encourage the practice of continuous improvement in user journeys, but there is some theoretical debate within that uniform agreement (Camgoz-Akdag et al., 2017; Frangeskou et al., 2020; Hydes et al., 2012; Improta et al., 2015; Matthias & Brown, 2016; McDermott et al., 2013; Murphy et al., 2019; Niemeijer et al., 2013; Radnor & Osborne, 2013; Rizan et al., 2020).

Identifying recurring patterns within and between patient pathways and SDL was instrumental in situating this dissertation within a broader theoretical background. The starting point for this study was to be found at the point of intersection in the midst of the SDL and patient pathways literature, but this position was slightly modified along the way to leverage off the systemic perspective. The recent trend is the academic movement on the patient pathway continuum from a linear approach towards the iterative nature of the agile methodology. This evolving discourse in the growing body of literature smoothed the progress of selecting, prioritizing, and assigning time and efforts to specific research

papers (Harris, 2019). Arranging works in dual disciplines facilitated productivity while reading and organizing the literature, seeing that it clarified which papers were outside the scope of the research (e.g., clinical studies). It became imperative to reflect on which scholars to align with, which to challenge, and which to disregard. In doing so, a few works were skim-read more lightly and superficially than others (e.g., Kuratko et al. (2001) study on corporate entrepreneurship strategy).

Service-Dominant Logic framing the theoretical lens of the study in healthcare has garnered an interest amongst service marketing scholars. Furrer et al. (2020, p. 308) labels it as a “*star service research topic*” to be reckoned with. Conducting an analysis and synthesis of highly cited papers served as a means to knowledge acquisition, and led to the conclusion that SDL thinking in patient pathways have been marginalized, under-represented, and under-researched. In light of this substantial research gap, the study embraces an inductive approach, characterized by an exploratory methodology that immerses itself in the exploration of meanings and experiences (Brewerton & Millward, 2001).

1.3 Pathway: a service engineering project

Against the backdrop of user journeys, Pathway is a service engineering project that aims to establish new knowledge, and a toolkit for managing and communicating patient pathways (SINTEF, 2021). The framework will consist of a theoretical foundation, a visual multi-layered modelling language, and supporting guidelines and methods. The final outcome will support and simplify the design, documentation, and implementation of pathways, thus enabling efficient communication among and across groups of healthcare professionals and patients. The project duration is 2021-2025 and is led by SINTEF Digital, and the cooperation partners are University of Oslo (UiO) and University of Aalto (SINTEF, 2021). Pathway are funded by the Research Council of Norway (RCN) through the scheme of health, care and welfare services research (HELSEVEL program) (The Research Council of Norway, 2021). As per the agreement with the project manager, Dr. R. Halvorsrud, this study was granted full research autonomy, and therefore, the master's thesis will not be bound by any restrictive clauses or protections.

1.4 Structure of master thesis

The master's thesis adheres to a structured framework, comprising seven core chapters: introduction, literature review, methodology, data collection and analysis method, results and discussion, conclusion and implications, and limitations and avenues for future research.

2.0 Literature review

The initial exploration of the SDL and patient pathway-related literature involved analyzing scholarly journal articles, conference proceedings, reports, and book chapters, yielding a thorough understanding of the academic terrain in these fields. Review articles, particularly valuable for summarizing current knowledge and findings, guided this exploration. On one hand, conducting a survey of scholarly knowledge equips researchers with a strong foundation, aiding them in building upon existing knowledge and identifying research gaps (Saldana et al., 2011). Exploring various sources facilitates a grasp of the subject, with review articles summarizing complex findings and streamlining information collation. Conversely, some scholars caution against rigid literature review approaches, highlighting the risk of prior literature influencing new data interpretation, leading to bias (Gioia et al., 2013; Glaser & Strauss, 2017). Ultimately, well-conducted reviews, coupled with awareness of biases, enhance study rigor. By acknowledging limitations and challenging assumptions, researchers uphold investigation integrity (Charmaz, 2014; Thornberg & Dunne, 2019).

2.1 Converging theoretical frameworks

The philosophical underpinnings of intertwining SDL and patient pathways may appear to some as tautological or possibly pleonastic, as it involves articulating akin ideas and phenomena through slightly divergent linguistic expressions (MacInnis, 2011). This impression emerges from the intrinsic interconnectedness of the explored concepts, which can lead to analogous conclusions reached through distinct theoretical perspectives. This overlapping nature, however, is not confined solely to the realms of marketing management and health operations management. The systemic perspective, which underscores the conception of coalitions as interconnected wholes rather than isolated components, is a concept that transcends various academic disciplines, for example biology, psychology, and sociology (Lusch & Vargo, 2014). In each of these domains, academics' endeavor to grasp the multifaceted interactions within their respective systems, often converging on analogous conclusions. The occurrence of theories yielding comparable outcomes through circular reasoning is a pervasive phenomenon across diverse academic disciplines (Flick, 2018). In the pursuit of knowledge, scholars build upon preexisting theories and empirical evidence, reinforcing and substantiating specific concepts through iterative cycles of inquiry and analysis. This iterative process may occasionally culminate in reinforcing loops where the conclusion echoes aspects introduced in the introduction, so to speak (Flick, 2018). Nevertheless, it is paramount to acknowledge that the fallacy of circular arguments serves to augment the dependability of the conclusions, furnishing a more robust foundation for further research and scholarly progress.

The amalgamation of SDL and patient pathway literature mirrors the natural evolution of scientific exploration, where concepts coalesce and advance successively (Flick, 2018; MacInnis, 2011). This underscores the universality of the systems logic and its pertinence in comprehending intricate

phenomena in the realm of healthcare and beyond. Instead of suggesting redundancy, this confluence of ideas underscores the depth of the systemic perspective and its versatility across different academic domains, fostering a more profound insight into interconnected structures and phenomena. As scholars persist in exploring and refining these concepts, their contributions enrich the corpus of knowledge and enhance various disciplines, encompassing healthcare and marketing management.

2.2 Searching for relevant literature

Extensive online searches were conducted on EBSCOhost, Scopus, and Web of Science to find relevant literature using keyword searches. Organizing the collected material was facilitated by documenting searches in an Excel sheet, including database, date, and keyword combinations. The sort-and-filter function aided in tracking key citations and passages. The limitation inherent in keyword searching, characterized by its divergence from the comprehensive nature of conceptual category searching, implies the potential omission of pertinent empirical evidence. To address this, alternative words with similar meanings were sought. A wide range of acronyms and abbreviations (e.g., Service-Dominant Logic and SDL) were explored. Pivotal terms, such as value co-creation, were also identified and added to enhance search specificity.

Both patient pathway and SDL literature employ specialized language, incorporated into database searches. For accuracy, Scopus's unique keyword sampling tool was used. During a simple introductory SDL search, the keyword *value co-creation* appeared 779 times among 9192 peer-reviewed articles. This exceeded occurrences of the *Service-Dominant Logic* keyword (509 times). In the same search, *healthcare* had 106 hits, while *health care* had 68 hits and *health services* had 86 hits. Minor spelling and vocabulary variations between British and American English, like healthcare and health care, were also evident. However, the combined search for patient pathway and SDL terms yielded no hits, suggesting that SDL has not yet permeated this facet of the sector.

The absence of hits in the combined search for patient pathways and SDL keywords was a noteworthy observation. It implied that, within the realm of patient pathway literature, the impact of Service-Dominant Logic likely is unexplored or underrepresented. The dearth of co-occurring literature between the literature streams may be attributed to several factors. Firstly, patient pathways by tradition focus on the clinical aspects of the service provision (e.g., the sequencing of medical interventions). While these are pivotal components of healthcare, they may not have been explicitly linked to marketing-oriented concepts. Secondly, the terminology used in the health domain often diverges from marketing terminology. Healthcare professionals and academics may not habitually employ marketing-related language when discussing patient pathways, potentially contributing to the limited overlap in the literature. Still, it's important to note that this lack of overlap doesn't necessarily imply a complete disconnect between these two domains. Rather, it suggests an opportunity for interdisciplinary exploration and knowledge exchange. As the healthcare sector moves forward and

adapts to changing patient needs and preferences, there is potential for SDL to offer fresh perspectives and innovative solutions for patient pathway management.

2.3 Survey of relevant literature

The online search was divided into two separate searches of patient pathways and SDL in Web of Science, a database known for rigorously evaluated journals. Lexicons for both literature streams have expanded over time, with various terms referring to the same topic with minor variations. For instance, pathways in oncology care settings were represented by synonyms, for example care pathways, clinical pathways, and more (Richter & Schlieter, 2021). Identifying these terms enabled fruitful independent keyword searches and facilitated original contributions to the field. Furthermore, to ensure the scientific rigor of the survey, a set of inclusion and exclusion criteria were used as premises for further logic. Foremost, the literature needed to be peer reviewed. Given the nascent nature of the research topic, the initial quest was restricted to scholarly sources published within the preceding decade. Lastly, the selected works had to be authored in English, Norwegian, Danish, or Swedish, as full professional proficiency is held in these languages exclusively.

Before the results were refined, 16 256 hits were registered in the patient pathway literature when the following keywords were selected in the Web of Science core collection: *"care pathway" OR "clinical care pathway" OR "clinical pathway" OR "network SOP" OR "optimal care pathway" OR "pathway map" OR "care path" OR "collaborative course of care" OR "integrated care pathway" OR "disease management plan" OR "patient pathway" OR "critical pathway" OR "care pathways" OR "clinical care pathways" OR "clinical pathways" OR "optimal care pathways" OR "pathway maps" OR "care paths" OR "integrated care pathways" OR "patient pathways" OR "critical pathways" OR "patient journey"*.

The search results were refined by the following parameters in Web of Science – type of document; article, meso level citation topics on a granular level; management, and categories; management or healthcare sciences services. Because of the small quantity of hits in the search results, a decision was made to extend the year of publication to 2001. At micro level, this encompassed nine topics; six sigma, knowledge management, social movements, intellectual capital, technology acceptance model, job and customer satisfaction, computer-supported cooperative work, and entrepreneurship. Inside the range of 38 results retrieved, 23 of which are placed in the six sigma category. A simplified first round of the review procedure made it easier to navigate through the jungle of literature, and to eliminate irrelevant sources. Amongst the 38 patient pathway peer-review articles, two studies were excluded because they were not conducted in the healthcare sector.

The Norwegian healthcare and pharmaceutical system are financed primarily through general taxes and payroll contributions (Norwegian Institute of Public Health, 2018). In contrast, citizens in other regions might encounter universal private, public, or public-private insurance systems, potentially

qualifying for subsidized coverage or remaining uninsured (The Commonwealth Fund, 2020). While acknowledging the significance of context in knowledge transfer, a notion that refining search results by region could enhance precision, only three patient pathway studies would emerge from a Scandinavian focus. Notably, South Africa is a single-payer healthcare system, and six other studies were conducted beyond the European borders (The Commonwealth Fund, 2020). Although five research papers were conducted in the US and one in Zimbabwe, both of which feature mixed-market healthcare service systems, it is believed that the conclusions and recommendations from these diverse continents would expand the understanding of the subject matter. Considering the adoption of a systemic perspective and making sound judgment, it is equitable to encompass studies conducted in non-Western nations. Consequently, the selected publications are deemed to be not only representative but also transferable to the context of healthcare provision in Norway.

As regards SDL, the keywords searched for in Web of Science, "*Service-Dominant Logic*" OR "*S-D logic*" OR "*service-dominant (S-D) logic*" generated 1 460 hits. The results were filtered by type of document; article, highly cited papers only, and categories; business or management. Categories that were left out are hospitality and leisure, sports, tourism, computer science information systems, environmental studies, information science library science, and regional urban planning. This resulted in 38 publications that had been cited a total of 8 971 times at the time of the search. Sorted by relevance to best match the query, the 20 top hits were ultimately selected. Performing control searches in Scopus and EBSCOhost confirmed that all three databases proved to be moderately overlapping and had access to more or less the same journals.

A compilation of peer-reviewed articles was assembled, comprising 36 patient pathways papers and 20 SDL papers. In addition, Lusch and Vargos (2014) seminal book was included in the foundational literature for the review. After obtaining a general overview of the extensive literature, a more in-depth reading ensued for each article. Color-coding was used to accentuate interesting passages identified during the study. Specific works were subject to more scrutiny, including critical appraisal (Harris, 2019). Studies of remarkable quality, exemplified by Schrijvers et al. (2012) warranted in-depth exploration, necessitating additional readings and a nuanced reinterpretation. Managing the extensive literature encompassed identifying key contributors and addressing variations in terminology, a time-consuming endeavor that prompted the establishment of limits, long-term objectives, and interim goals (Saldana et al., 2011). The export feature of Web of Science, which encompasses abstracts, proved to be advantageous in the initial review process. This phase involved a thorough examination of titles, abstracts, and concluding sections, providing a thorough understanding of each paper's academic contribution. The reference lists of these papers were scrutinized, with a particular focus on recurring author names, leading to the identification of complementary concepts and theories. The inclusion of citations from key authors in the literature served as a strategy to bolster the review's credibility,

exemplified by the works of Vargo and Lusch (Saldana et al., 2011). In the ultimate theoretical discourse, all papers in the selection were synthesized and interpreted.

2.4 A new logic of marketing: Service-Dominant Logic

A new logic of marketing was presented by Vargo and Lusch (2004) in the *Journal of Marketing*, better known as Service-Dominant Logic, as an enhanced way of explaining value creation (Lusch & Nambisan, 2015; Lusch & Vargo, 2014; Skalen et al., 2015). Lusch and Vargo (2014, p. 18) raise objections to the presiding Goods-Dominant Logic by stating: “*there is no new services economy, there are no services, there are no producers and consumers, enterprises cannot create value independently, enterprises are relatively unbounded, and markets do not exist*». The conceptual transition from a Goods-Dominant Logic to a Service-Dominant Logic is hard given that the traditional notion of value creation has become a fundamental and inherent viewpoint in any a set of principles or procedures according to which any one thing is completed. Yet, there is no factual transition to a service economy, since “*all economies are service economies*” (Langley et al., 2021; Lusch & Vargo, 2014, p. 54; Vargo & Lusch, 2016, p. 8). Products to the core can be explained by SDL, as well.

Goods-Dominant Logic with the commodity in the center of attention fails to explain the dynamic and complexity in bringing together resources from various actors. GDL holds that goods are “*embedded with utility (value) during the production*” (Lusch & Vargo, 2014, p. 32). The aphorism articulated as, “*the purpose of the enterprise is to produce and sell value-laden goods*» can be effectively transmuted into the assertion that once a commodity has reached the production stage, no further value creation occurs (Lusch & Vargo, 2014, p. 16). Instead, the value is merely consumed or extinguished. The shift away from material goods has major consequences for the perception of marketing management and value creation – and how the whole exchange system is put together. With that being said, SDL is to a greater extent a universal perspective, in comparison with GDL which merely considers one particular section in a domain.

Along these lines, the logic account for principals of management, thus, explain in a sharper way how the external environment works as opposed to the SWOT analysis or Porter’s five forces framework (Lusch & Vargo, 2014). Through the incorporation of a novel marketing paradigm, it becomes apparent that macroeconomic factors can be construed as endogenous, as opposed to exogenous, given their inherent origin within the system itself (Alexander et al., 2018; Jaakkola et al., 2015; Nadeem et al., 2021; Vargo & Lusch, 2016). In the past, managers’ aim has by tradition been to gain market share from competitors – as if the marketplace is a fixed entity whose volume scarcely varies. In reference to Lusch and Vargo (2014, p. 18) claiming that markets cease to exist, advanced spheres are formed and transformed each and every time one or more actors converge and establish structures that add up to the arena (Lusch & Vargo, 2014). This way of explanation is abstract and analytical, but then again fine points are essential to in-depth comprehend the full narrative. To illustrate this, a medical clinic

hardly exists unless suppliers deliver cargoes and patients go to the doctor's office. Even though it is with great certainty the clinic won't disappear overnight because people need medical care and treatment. Nevertheless, the medical clinic is recreated every time the set of connections crowd and act together.

A revised dominant logic impacts the development and deployment of communications and management strategy, from operating in a stable and predictable unit to a dynamic and complex unit (Vargo & Lusch, 2017). Besides, SDL changes the view on technology, as well as how service innovations occur and are spread in the healthcare sector (Jaakkola et al., 2015; Lusch & Nambisan, 2015; Skalen et al., 2015). If so, a new lens must be adopted. By shifting the perspective from GDL to SDL a number of changes transpire. The greatest challenge is to re-set the mindset from a product-driven orientation, to focusing on the skills that are exchanged, and the services that are provided in the interaction and value creation (Langley et al., 2021; Lusch & Vargo, 2014).

2.4.1 Institutional arrangements and value co-creation

Reading between the lines in Lusch and Vargo (2014), axiom 5 and FP11 is vaguely implied. Soon after, Vargo and Lusch (2016, p. 18) put it into words as “*value cocreation is coordinated through actor-generated institutions and institutional arrangements*”. Institutions can be seen from two angles, and organizations are not it. They set their sights on structures and mechanisms that keep the social order organized as a means to guide and coordinate behavior and activities and value co-creation within a service-ecosystem (Vargo & Lusch, 2016, 2017; Vargo et al., 2015). Institutions are referred to as “*humanly devised rules, norms, and beliefs that enable and constrain action and make social life predictable and meaningful*” by Vargo and Lusch (2016, p. 11) is also going by the name of “*rules of the game*” (Lusch & Vargo, 2014, p. 25) Furthermore, institutional arrangements or logics are “*higher-order assemblages of interrelated institutions*” (Vargo & Lusch, 2017, p. 49). Social units in the world as we know it is built on actor-made norms, rules, and values separating right from wrong (Alexander et al., 2018; Hollebeek et al., 2019). Some institutional arrangements apply in society as a whole, regardless of factors such as geographic location, culture or industry standards.

For example, Norwegian health authorities removed regulatory guidelines against covid-19 in February 2022, while the Chinese government to this date still maintains movement and quarantine set of arrangements. Plus, a variety of regulations may only apply to certain actors (e.g., a chief public health officer can set restrictions within the municipal boundary). In an informal fashion, individuals or collective entities adhere to their self-established regulations, which may or may not align with regional or national regulatory bodies (Lusch & Vargo, 2014). Consequently, subcultures can emerge within the societal framework, as relational agreements within workplaces or familial units materialize during the collaborative creation of value, irrespective of the legal and accessible resources. For instance, disparities in the execution of basic medical procedures between various departments within a local hospital underscore this phenomenon (Jaakkola et al., 2015; Lusch & Vargo, 2014). Conflicting

norms or rules may appear in groupings depending on their point of view or group affiliation. By viewing society at a low level of abstraction, greater differences emerge in norms and rules (Alexander et al., 2018; Langley et al., 2021).

Institutionalization in service ecosystems is the “*shared acceptance of concepts, meanings, and normative behaviors*” (Lusch & Vargo, 2014, p. 18). In relation to technological innovation Vargo et al. (2015, p. 63) comparably refer to this concept as “*the maintenance, disruption and change of institutions*”. In the case of GDL, institutionalization in markets and economies is often recognized as *performativity*, meaning that “*markets are seen as being continually performed and shaped by multiple actors*”(Vargo et al., 2015). For actors to play roles in accordance with institutionalized conceptualizations subsequently point towards a strive for self-realization of own capacities (Lusch & Vargo, 2014). In other words, it is the pursuit of fulfilling actors’ responsibilities that guides and gives consistency of human life.

2.4.2 Exploring the dynamics of service ecosystems

Hollebeek et al. (2019, p. 166) refer to *service systems* as “*value cocreation configurations of people, technology, organizations and shared information*”, exemplified by municipalities, workplaces or hospitals (Maglio & Spohrer, 2008, p. 18). Similarly, Huotari and Hamari (2017, p. 24) define service systems as “*an arrangement of resources (including people, technology, information, etc.) connected to other systems by value propositions*” (Vargo et al., 2008, p. 145). Beyond doubt, the service ecological unit construct draws on design thinking in service science (Hollebeek et al., 2019; Huotari & Hamari, 2017; Jaakkola et al., 2015; Langley et al., 2021; McColl-Kennedy et al., 2012; Ranjan & Read, 2016; Rather et al., 2019; Vargo & Lusch, 2017). A service ecosystem stands for a “*relatively self-contained, self-adjusting system of resource-integrating actors, shared institutional logics, and mutual value creation through service exchange*» (Lusch & Vargo, 2014, p. 161). According to this definition, there are a handful of terms given explanation for in detail. The principal modification of the service ecosystem definition is that it favors institutions rather than information technology in service design (Vargo & Lusch, 2017).

Ecosystems and biodiversity in biology and zoology is a suitable metaphor for service ecosystems composed of diverse actors and resources to be self-contained and self-adjusting (Alexander et al., 2018; Lusch & Vargo, 2014; Vargo & Lusch, 2017). The exception is that humans have developed an intrinsic and sophisticated set of rules to get by and relationships in daily life among actors. Lusch and Vargo (2014) may not label a service system to be sustainable, but the ability, viability and survival skills is essential to completeness, above all due to digitalization (Lusch & Nambisan, 2015). As soon as plants or animals die, a fresh ecosystem comes into being around the remains. Likewise, new opportunities arise after a company goes bankrupt. Not every bit of resources disappear, in the sense that physical assets can be sold, and former employees find other jobs and contribute into separate, yet nested service ecosystems (Alexander et al., 2018; Jaakkola et al., 2015; Lusch & Vargo, 2014; Vargo

& Lusch, 2016, 2017; Vargo et al., 2015). Thus, the dynamical and multidimensional development in service ecosystems makes it hard to fully comprehend all links and interactions between nodes. As opposed to plants and animals, humans are capable of making conscious choices which adds to the complexity (Kumar et al., 2019; Rather et al., 2019; Vargo & Lusch, 2016).

Taking on an interactive and systemic viewpoint as opposed to dyadic interactions, is key to understand value co-creation occur through service exchange in terms of how resource integration is interconnected with institutions and institutional arrangements (Alexander et al., 2018; Brodie et al., 2019; Jaakkola et al., 2015; Vargo & Lusch, 2016, 2017; Vargo et al., 2015). By dint of going after the product, the intricate play of resources and forces as point of reference fades away. In other words, SDL has greater ability to explain the subject matter effectively to which it appertains to. Yet, Lusch and Vargo (2014) points out that SDL is not a perspective in competition with GDL, hence it is not an either-or situation. The goods-dominant model is a special case of frozen activities added to a product (Lusch & Vargo, 2014). FP2 posits that “*indirect exchange masks the fundamental basis of exchange*” (Lusch & Vargo, 2014, p. 58). To illustrate this, all the skills and knowledge of healthcare professionals required for covid-19 testing is a masked service for identifying current infection at individuals – in which can be to some extent obtained by self-testing at home for that matter. Namely, the systems logic is an overlying perspective. The terminology relied on in a GDL- phase can still be made use of, but it must be understood in a limited context of informed activities resided by knowledge (Lusch & Vargo, 2014).

Having in mind the rhetorical expression of self-sustaining ecosystems put across that it creates value without resources from the outside (Lusch & Vargo, 2014). However, a distinction is drawn between an open and a closed system, lets say, a cash register has a closed system (Lusch & Vargo, 2014). No matter what external impact, the system will not change. It is stable and lacks adaptation from the outside world. The better the closed system is, the better the system will take care of its function. In the context of artificial intelligence, Langley et al. (2021) present a pragmatic approach that offers a perspective on why this differentiation is significant in the context of marketing management.

Throwing actors into the mix converts the system into being open to one degree or another (e.g., depending on the situation a population is fairly self-contained as it adapts to changes in surroundings) as well as fairly constant and resilient. Grönroos and Voima (2013) similarly refer to closed and open systems, but they apply the term value creation spheres in favor of service-ecosystem.

2.4.3 Unveiling the layers of influence

In order to have a clear vision of the influence of institutions, it is useful to structure the philosophy of life into three layers of aggregation, namely, micro, meso, and macro (Alexander et al., 2018; Brodie et al., 2019; Langley et al., 2021; Lusch & Vargo, 2014; Vargo & Lusch, 2016, 2017; Vargo et al., 2015). That being said, the apprehension of the world can be divided into an infinite number of layers, but these three layers are most appropriate for being an analytical tool to recognize occurrences in

service ecosystem interactions. Considering that Lusch and Vargo (2014, p. 169) favors a systemic structuration by stating that “*service ecosystems are multi-level in nature*”, Grönroos and Voima (2013) and Aarikka-Stenroos and Jaakkola (2012) undertake a micro level approach, by the means of centering around direct transactions between the customer and the service provider.

The meso level implements an additional stratum of resources, norms, and regulations, encompassing entities such as communities, families, or industries (Vargo & Lusch, 2016, 2017). The broader social environments can be situated within the macro-level domain. For instance, Norwegian legislation exerts its jurisdiction across all strata of actors, irrespective of their specific industry or corporate lineage, or the nature of the two-party relationships involved (Vargo & Lusch, 2016). Alexander et al. (2018, p. 338) zoom further out and introduces a fourth meta level, defined as “*multiple, co-existing service ecosystems, such as sectors or industries*”. Similarly, Lusch and Vargo (2014, p. 163) explains that service systems are “*often nested within or are part of another, larger service ecosystem*”.

Employing the tripartite structural framework affords a multifaceted perspective on the ecosystem, enabling an examination from distinct vantage points. The interrelations among these tiers are delineated as vertical causality, encompassing both downward and upward causal influences. For instance, phenomena emerging at the micro-level exert discernible effects on the mezzo and macro levels, thereby illustrating the intricate dynamics of this multi-layered system (Lusch & Vargo, 2014). To illustrate upwards causality, consider innovators and early-adopters that embrace a new technical innovation until it eventually becomes the new standard in society. Downwards causality is better known as society’s regulations that set guidelines for behaviors at the individual and group level. So to speak, logical reasoning exists for consistency in the rules and norms but is constantly developed through upwards and downwards causality.

2.5 Patient pathways

The European Pathway Association (EPA) defines patient pathways as “*a methodology for the mutual decision making and organization of care for a well-defined group of patients during a well-defined period*” (Improta et al., 2019, p. 3; Schrijvers et al., 2012, p. 1; Torseth & Adnanes, 2022, p. 2). The aim of patient pathways is to “*enhance the quality of care across the continuum by improving risk-adjusted patient outcomes, promoting patient safety, increasing patient satisfaction, and optimizing the use of resources*” (Schrijvers et al., 2012, p. 2). It is often portrayed as a sequential pattern of touchpoints formalized in the chronological order that they must be executed in (e.g., Cherif et al., 2020; Feyrer et al., 2006; Hydes et al., 2012; Improta et al., 2015; Improta et al., 2019; Ludwiczak, 2021; Rizan et al., 2020). The mapping techniques range from infallible post-it notes and text-box diagrams, to more sophisticated flowchart representations using pictorial and stylized sets of icons distinguishing between action and communication points. Ludwiczak (2021) depicts a typical linear representation, explicitly, before, during, and after a healthcare service delivery. While Matthias and

Brown (2016, p. 1439) define healthcare as “*a service experience for all patients*”, other scholars consider it as a function of institutions (e.g., hospital or medical practitioner).

With regard to measurement, analysis and improvement, value stream mapping (VSM) is constructive to a greater extent in order for healthcare to become process oriented (Camgoz-Akdag et al., 2017; Frangeskou et al., 2020; Hydes et al., 2012; Improta et al., 2019; Ludwiczak, 2021; McDermott et al., 2013; Ponsignon et al., 2018; Rizan et al., 2020). Process mapping demonstrates the same flowchart diagram, or as a minimum practically indistinguishable attribute as VSM (Chirenda et al., 2021; Foglia et al., 2022; Frangeskou et al., 2020; Hydes et al., 2012; McCracken & Edwards, 2017; Mould et al., 2010; Murphy et al., 2019). Both administrative and clinical steps of the patient pathway are graphically mapped in VSM, although levels of abstraction are highly variable (Murphy et al., 2019). The difficulty with mapping of individual patient journeys over extended periods of time is to provide systemic thinking to understand the whole care network, along with touchpoints in sufficient detail (Mould et al., 2010).

A recent development in the patient pathway literature is the introduction of health operations management, evolved from the economic optimization and industrial economy branch in macroeconomics (Frangeskou et al., 2020; Matthias & Brown, 2016; McCracken & Edwards, 2017; Ponsignon et al., 2018; Schrijvers et al., 2012; Williams & Radnor, 2022). Health OM is described as “*the analysis, design, planning and control of all the steps necessary to provide a service to a client*” (Schrijvers et al., 2012, p. 2). Williams and Radnor (2022) draw on new public management literature and provides an eightfold framework for sustainable public service operations (i.e., innovation, value, relationships, environment, system, staff, experience, and co-production).

Health OM pertains to the systematic minimization of impediments inherent to temporal and spatial factors, encompassing processes such as inter-hospital and intra-hospital patient care transitions, as well as the management of concurrent activities transpiring across disparate sites (Improta et al., 2019; Matthias & Brown, 2016; Schrijvers et al., 2012; Williams & Radnor, 2022). Health OM acknowledges the difficulty of the undertaking and endeavor to reduce two-dimensional issues by the means of resource coordination, that is, how people, technology, and materials may be organized given service characteristics (Feyrer et al., 2006; Gemmel et al., 2008). That may be linked to variations in demand, volumes, or patient interaction. How will pathways inside, around and in between healthcare actors meet patient demands and expectations?

There is no lack of Health OM buzzwords in the patient pathway literature – six sigma, lean six sigma, lean process design, lean thinking, total quality management (TQM), continuous quality improvement (CQI), the Kaizen approach, patient flow, hospital process orientation (HPO), critical path method (CPM), program and evaluation technique and review (PERT method), VSM, Pareto charts, demand and capacity calculations, business process approach (BPA), just-in-time (JIT), business process reengineering or redesign (BPR), Ishikawa diagrams, flow logic, value-based healthcare (VBHC),

theory of constraints (ToC), and customer order uncoupling point (COUP) (Camgoz-Akdag et al., 2017; Clark et al., 2014; Frangeskou et al., 2020; Gemmel et al., 2008; Hydes et al., 2012; Improta et al., 2015; Improta et al., 2019; Matthias & Brown, 2016; Mould et al., 2010; Niemeijer et al., 2013; Rizan et al., 2020; Rolls et al., 2020; Schrijvers et al., 2012; Wackers et al., 2021; Williams & Radnor, 2022).

Lean thinking is the umbrella term that covers a broad category of business decision making processes intended for value growth by means of increased resource productivity (Matthias & Brown, 2016). Hence, JIT and six sigma are particularly hard to differentiate from lean (Schrijvers et al., 2012). The management philosophy can be traced back to the 1930s, and radically changed the work methodology of first and foremost in Asian large-scale manufacturing industries, for instance, Toyota and Motorola (Matthias & Brown, 2016; Rizan et al., 2020; Wackers et al., 2021). Transferred to the healthcare environment, the aim is to implement and manage top-quality pathways in line with leans overarching principles, specifically, high speed, predictability, solidity, flexibility and cost-reduction (Improta et al., 2015; Matthias & Brown, 2016; Niemeijer et al., 2013; Rizan et al., 2020).

Gemmel et al. (2008, p. 1215) attest to the truth of the health milieu being “*fundamentally different from the business sectors*”. Relational supervision puts emphasis on system-wide relationships, viz., knowledge sharing and collaborative policymaking, and patients’ co-production with healthcare professionals (Ponsignon et al., 2018; Williams & Radnor, 2022). Bringing a business mindset into public services can get in the way of seeing what’s truly taking place in the pathways. Financial statements in health OM are often abstract, non-operational, and aggregated, leading to acts of dehumanization, perhaps, less personal touchpoints (Schrijvers et al., 2012). Patient pathways that undergo an agile transformation are characterized by the deliberate removal of bottlenecks and the systematic elimination of friction in the relentless pursuit of excellence (Mould et al., 2010). Waste is the central term in lean well-defined as non-value adding activities, exemplified by excessive touchpoints, adjusting for errors, non-existent communication between functions, not inevitable patient transportation, or service offers in excess of patient requirements (Hydes et al., 2012; Rizan et al., 2020). Value-enhancing endeavors can be effectively orchestrated through the strategic implementation of Total Quality Management (TQM) or Continuous Quality Improvement (CQI). For instance, optimization measures, such as the reduction of nursing staff requirements, can be achieved by crafting patient pathways to minimize inter-facility transitions (Wackers et al., 2021). Albeit JIT scholars tend to regard value as “*quality divided by costs*” – clinical, operational, and experiential well-being must be understood from the patient’s perspective (Hydes et al., 2012; Wackers et al., 2021, p. 2).

2.5.1 Lean vs. waterfall pathways

By and large, there are two stereotypical and possibly contradictory modes of patient pathways (Hydes et al., 2012). One end of the pathway spectrum seeks optimum efficiency at every phase, while the

opposite extreme accentuates maximum flexibility and complexity. The former may be put a label on as waterfall patient pathways and the latter is labeled as lean pathways (Bernacki et al., 2021; McCracken & Edwards, 2017; Rizan et al., 2020; Schrijvers et al., 2012). Waterfall patient pathways are based on ideas of standardization, new public management, and top-down master planning, as opposed to JIT acting on patient variations in symptoms and treatment responses (Bernacki et al., 2021; Matthias & Brown, 2016; Torseth & Adnanes, 2022; Williams & Radnor, 2022). The waterfall approach corresponds well to the healthcare providers view, and the lean methodology adequately reflects the patients journey and “*evaluation of his or her actual experience*” (Ponsignon et al., 2018, p. 2331). Ergo two common strategies are cost-leadership or differentiation strategies, according to Porter’s generic competitive strategies (Kuratko et al., 2001).

A waterfall pathway may seem ideal at first glance, but due to clinical, technical, and administrative errors and shortcomings, which manifest as system failure, delayed diagnosis, or inadequate follow-up after treatment, the blueprint can become socially, economically, and environmentally unsustainable (Bernacki et al., 2021). Torseth and Adnanes (2022, pp. 1-2) found that “*clinicians often have mixed or negative attitudes regarding the standardization of health care utilizing pathways*”. On top of that, the degree of unlikeness between standards for motivational and planning purposes have been unintentionally or deliberately overlooked (Veld & Alfes, 2017). Conforming to a standard “*limits variance by reducing the range of stimuli, decision opportunities and behaviors available to an actor*” (Wilhelm et al., 2020, p. 1171). To have excessively confidence in routines reduces the patients scope for maneuver in making informed decisions (Schrijvers et al., 2012).

Patient pathways characterized by lean methodologies exert a more profound endeavor in their pursuit of patient-centered care. This is achieved through the implementation of a pull strategy, primarily directed at mitigating the prevalent issues of disarray and inefficacy within established protocol (Hydes et al., 2012; Rizan et al., 2020). That is well-functioning provided that the actual patient lead time is shorter than the expected patient lead time, meaning, total period of time of patient journeys (Hydes et al., 2012; Murphy et al., 2019; Rizan et al., 2020). If that’s not the case, feed-forward control and push management planning is de rigueur to a certain degree, exemplified by organizational preliminary controls to identify and prevent deviations and outliers of the standards (Kelly et al., 2017; Schrijvers et al., 2012; Wackers et al., 2021; Wilhelm et al., 2020). The waterfall model offers greater systematic coherence that might shorten the duration of the pathway, and help to overcome lack of resources, limiting the risk of sanctioning and errors, and inconsistent professional socialization among junior physicians (Schrijvers et al., 2012; Wilhelm et al., 2020).

Strong parallels of patient pathway modes can be drawn towards classical push versus pull strategies. By tradition, a push strategy is an American-inspired and multi-tiered production strategy, characterized as being result-oriented by focusing on the outcome rather than the service delivery process, such as timing of surgery preparations (Bernacki et al., 2021; Hydes et al., 2012; Murphy et

al., 2019; Schrijvers et al., 2012). The overall goal is to predefine the optimum blueprint for streamlining the patient pathway on the account of a chain of command structure, typical of hospitals (Mould et al., 2010; Murphy et al., 2019; Rizan et al., 2020). The cost-efficiency and economizing nature inherent in the uniform, standardized patient pathway is predicated on a push system. The prevalence rate, for instance, signifies the ratio of patients afflicted by a specific ailment at a particular juncture (Cherif et al., 2020; Clark et al., 2014; de Bont et al., 2016; McDermott et al., 2013; Wilhelm et al., 2020).

In contrast, the lean cycle is all the more so sensitive to the affected roles' values, preferences and expressed needs, in conjunction with increasingly fragmented patient journeys, that is, a pull strategy (Camgoz-Akdag et al., 2017; Frangeskou et al., 2020; Hydes et al., 2012; Improta et al., 2015; Aarhus et al., 2019). In a less rigid and bottom-up approach to planning, top executives or middle level of management are not the key actors (Kelly et al., 2017; Rizan et al., 2020; Torseth & Adnanes, 2022). Testimonies from patients, next-of-kins and affected healthcare professionals in the value constellation is contingent upon arriving at conclusions in activities intended directly or indirectly to improve or maintain a state of well-being. Holistic and patient-centered patient pathway studies in Australia, the UK, Ireland, and Italy, are commonly associated with JIT processes (Improta et al., 2019; Ly et al., 2021; McCracken & Edwards, 2017; McDermott et al., 2013; Murphy et al., 2019; Williams & Radnor, 2022). For health OM scholars, lean thinking is considered to be the state-of-the-art of patient pathway practice (Hydes et al., 2012; Rizan et al., 2020; Schrijvers et al., 2012).

Ultimately, both lean and waterfall approaches converge in their overarching objective of aligning the strategic healthcare agenda with the imperative of improving public health while effectively responding to patient needs and expectations. The sharp distinction between modes is contingent on the level of prediction and future estimations, such as patient lead times (Matthias & Brown, 2016; Rizan et al., 2020). In waterfall pathways, a pre-designing function of the various units is prepared by a central authority, as opposed to patients acquiring knowledge, and assessing alternative resolutions against the criteria's (Bernacki et al., 2021; Frangeskou et al., 2020; Hydes et al., 2012). Namely, the standardization of care processes to cancer patients introduced by Norwegian and Danish health authorities is a result of careful planning (Torseth & Adnanes, 2022; Aarhus et al., 2019). Pushing policymaking criteria away from the action of function will promote the flow of value to patients. Meaning that pathways must be shaped by the patients – not the other way around.

In the sphere of lean, patients are assumed to have an intermediate or proficient level of health literacy, rendering them self-reliant (McDermott et al., 2013; Schrijvers et al., 2012). This perspective bears relevance to the principles of activity-based costing, a method for calculating costs per patient rather than costs per unit, with an emphasis on the uninterrupted flow of processes between units, as opposed to isolating separate activities (Chirenda et al., 2021; Foglia et al., 2022; Murphy et al., 2019). The calculation of pre-determined costs per patient or average treatment time contributes to the design of

healthcare facilities wherein operational-level managers are relieved of the need to engage in resource allocation trade-offs concerning flexibility, productivity, and cost (Chirenda et al., 2021). At the operational level, these financial decisions are invisible because of the boundaries of external control managers are faced with.

The underlying idea of health OM is that smooth patient pathways stem from lean governance structures to ensure flow between activities and reduction of waste. A lean approach ought to be understood in lateral terms (i.e., horizontal relationships), thus adaption between sequentially connected healthcare service providers is at the center of attention (Matthias & Brown, 2016; Murphy et al., 2019; Rizan et al., 2020). Although their framework remains conceptual, Frangeskou et al. (2020) flow logic is based on optimum chronological sequence, timing of activities, management of resources to avoid bottlenecks, and co-ordination of information sharing. In an organic flow of patients between units, planning – if any – is done towards middle or closing stages of the journey (Hydes et al., 2012). Planning flows backwards and patient’s physical and psychological needs are met in reverse order, to be exact, zero-based planning (Matthias & Brown, 2016). The terminal segment of the value chain governs operations in a manner where planning transcends the traditional top-down approach and, in essence, shifts its trajectory upwards. This realignment seeks to synchronize clinical, technical, and administrative functions with the ultimate goal of enabling direct and responsive adjustments to align with the evolving requirements of patients, akin to the principles of JIT. Per contra, Matthias and Brown (2016, p. 1448), asserts that the process of strategy implementation “*starts at the top, devolves to the clinical directorates and then aggregates back up*”, subsequently devolving authority and decision-making responsibilities to the clinical directorates. These distributed actions and initiatives then culminate in an aggregation of information, insights, and outcomes, reuniting at the upper levels of the hierarchy.

With the proviso that the waterfall pathway is to be understood as forecast standards and troubleshooting, could bring about miscalculations in the volatile setting of healthcare (Mould et al., 2010). Bernacki et al. (2021, p. 5) found that “*assumptions and institutions of traditional care are being challenged*” to the point that professionals are not in a position for the time being to trust in the established protocols. For that reason, hierarchical management is a poor governance solution and should be replaced by a flat organizational structure (Gemmel et al., 2008; Schrijvers et al., 2012). Communications and information sharing across horizontal functions is seldom an easy task that calls for incentives, objectives, and performance reporting (Frangeskou et al., 2020). In that case, cost calculation and high-performance work systems have powerful behavioral effects – both functional and dysfunctional (Veld & Alfes, 2017).

A vertical mindset preserves status quo and discrepancy minimizations, in succession detracting from just-in-time and agility. Management control system functions keep personnel on a tight rein, giving rise to mistrust in the workplace (Schrijvers et al., 2012; Torseth & Adnanes, 2022). With regards to

information asymmetry, healthcare management administrators may lack sufficient knowledge or experience about the task they evaluate. Building up borders around each and every function leads to bureaucratic silos within the realm of possibility (Frangeskou et al., 2020; Gemmel et al., 2008). Governance of hierarchically assigned responsibilities from an arm's length give rise to islands of performance management, or isolated functions of the pathways (McDermott et al., 2013; Veld & Alfes, 2017). To increase efficiency separately in primary and specialist healthcare is at the opposite pole of lean. Comparably, by what method time-driven ABC proposes to calculate costs per. patient construct a standard to obtain on account of checking for deviations (Chirenda et al., 2021; Foglia et al., 2022). Lean thinking brings forwards that cost calculations also need to be agile, or simple – complex ABC-calculations are a waste.

Albeit it may appear as if agile practices are superior to waterfall patient pathways at this point, that is not a given. Matthias and Brown (2016) conclude that the success rate of lean shows a discrepancy in public healthcare services. Murphy et al. (2019, p. 49) support the existing argument and underlines that “*flow orientation in healthcare systems is often inadequate*”. Moreover, the “do-more-with-less” frame of mind has had a negative impact on employees and patient satisfaction (de Bont et al., 2016; Frangeskou et al., 2020; Schrijvers et al., 2012). Lean thinking serves as a valuable managerial instrument for maintaining immediate control and enhancing operational efficiency. However, its utility diminishes when applied to proactive, future-oriented endeavors, such as patient discharge planning (Clark et al., 2014; Torseth & Adnanes, 2022). In other words, lea(r)n as you go. Medical complications and variation are better tackled by a waterfall pathway since every single incident can be computed into the plan of action, but then again it comes at a high cost (Murphy et al., 2019). Seeing that unforeseen circumstances bring to light the Achilles' heel of lean thinkers, JIT methods may prove to be hard for healthcare executives to implement in practice.

2.5.2 Advocating for a fluid approach to pathways

The history of the patient pathway literature does not only explain the past, but also communications, information technology advancements, and the recently developed health OM in the public sector. Since the 1990s, process orientation has been favored which has matured into lean thinking (Mould et al., 2010; Schrijvers et al., 2012). As academics continues to recommend new (wine in old bottles) techniques (e.g., six sigma, Kaizen or HPO) in consort with words of warning about the after-effects of rejecting them – has led to a fundamental change in the approach and underlying assumptions of patient pathways (Gemmel et al., 2008; Improta et al., 2015; Improta et al., 2019; McDermott et al., 2013; Murphy et al., 2019; Niemeijer et al., 2013; Rizan et al., 2020; Wackers et al., 2021; Williams & Radnor, 2022). Especially with respect to financial and non-financial performance measures (Matthias & Brown, 2016). Not only are intra-organizational matters of paths becoming more intellectually and technologically advanced, pertaining to cost control, HRM or clinical risk management (Improta et al., 2015; McCracken & Edwards, 2017; Veld & Alfes, 2017; Wackers et al., 2021). At the present time, pathways encompass deeper, broader and artier inter-organizational, strategic, multicultural, and

international concerns. Even change management and value creation by the means of knowledge management, process orientation, and on-the-ground share leadership are taken account of (Feyrer et al., 2006; Gemmel et al., 2008; Matthias & Brown, 2016; McDermott et al., 2013; Rizan et al., 2020; Wackers et al., 2021). In the future, academic works are expected to jump on the bandwagon and pick up on up-to-the-minute JIT methodologies (e.g., kanban, scrum, or even scrumban).

The existing body of literature implicitly narrates the bright vs. the dark side, whereas agile methodology is modern, and traditional plan-do-check-act cycles are outdated (Bernacki et al., 2021; McCracken & Edwards, 2017). Taking the comparison to the extreme, the beforementioned emphasizes high speed, flow orientation, responsiveness, decentralization – alpha and omega is that lean pathways are patient-driven (Cherif et al., 2020; Clark et al., 2014; Frangeskou et al., 2020; Gemmel et al., 2008; Hydes et al., 2012; Rolls et al., 2020). Key lean principles in the company of soft skills drive value creation and a culture of performance in healthcare. Cost-effectiveness in isolation is simply a goal, but in world-class lean thinking non-financial objectives are just as, if not more, important seeing as healthcare providers strategy has shifted. A JIT mindset combines differentiation and cost-leadership in conjunction with competitive strategies (Kuratko et al., 2001). Linear care planning is characterized as being slow, hierarchical, historically focused, bureaucratic, organizational oriented, and centralized based on ideas of Taylorism and Max Weber (Bernacki et al., 2021; de Bont et al., 2016; Improta et al., 2015; Kuratko et al., 2001; McCracken & Edwards, 2017; Schrijvers et al., 2012; Torseth & Adnanes, 2022; Williams & Radnor, 2022). Accordingly, healthcare actors cannot become patient-focused and search for opportunities of growth by gazing in the rearview mirror.

Be that as it may, the collapse of the conventional waterfall patient pathway is far beyond the bounds of possibility. Besides, it may not be the case that waterfall patient pathways are in sharp contrast to lean thinking. Rizan et al. (2020) undertake a hybrid management style and O'Brien et al. (2015, p. 6) refer to flexible standardization, by which “*provides a structure to convey important clinical information with relevant defined patient information*”. Benchmarking and milestones in project management to measure the performance and success of pathways while adapting to the unexpected, have driven engagement from the clinical community. A fluid and cyclic approach by Ly et al. (2021) and McCracken and Edwards (2017, p. 10) may well represent the best practice today heavily focused on “*incorporating both structured and unstructured communication methods*”.

Murphy et al. (2019, p. 46) emphasizes “*the need for ‘Lean Thinking’ to become a cultural movement or ‘organisational philosophy’, requiring both a ‘top down’ and ‘bottom up’ approach within organisations*”. Correspondingly, Wackers et al. (2021, p. 9) states that “*top-down leadership might, however, facilitate bottom-up engagement*”. Direct follow-up and monitoring of patients and processes seems to be effective, even in a JIT strategy (Wilhelm et al., 2020). Instead of the negative reactions following the literal meaning of carrot-and-stick management and monitoring, self-regulation and

control by its very nature can take on an instrumental role for dialogic step-by-step decision-making processes (Kuratko et al., 2001). Matthias and Brown (2016) stand out from the literature by coupling lean to the strategy development in competition with the strategy implementation perspective. The apparent authority requirement for organizationally set objectives with the intention of preventing misunderstandings and miscommunications, is overlapping in duration with patients dynamically participating making choices by identifying a decision (de Bont et al., 2016). Subsequently, it's not a feasible solution to apply neither lean creativity nor waterfall-controlled pathways – maximum patient empowerment nor rigorous performance management and minimizing the sum of absolute deviations (Veld & Alfes, 2017).

In truth to be told, the active or passive usage of patient pathways takes precedence over the layout by and of itself. It is indisputably hard to become process oriented if pathways are managed in a rigid fashion, for example fixed, annually, or ritually (Hydes et al., 2012; McCracken & Edwards, 2017; Torseth & Adnanes, 2022). A flexible and constructive structure enables process orientation and continuous improvement, let's say, update, debate on, and challenge the ancient régime (Gemmel et al., 2008; Mould et al., 2010). A mere fraction of scholars demonstrate limited engagement with the design aspects of patient pathways, focusing their attention primarily on the execution and the resultant benefits derived from these pathways (Kelly et al., 2017; Ludwiczak, 2021). Ludwiczak (2021, p. 31) concludes that the “*existing literature does contain many practical examples of the use of customer journey mapping in public organizations*”. By way of explanation, the handling of the patient pathways tips the scales against how it is designed. For instance, Kelly et al. (2017) advises knowledge translation and taking action on the findings in patient journey mapping. To further illustrate this, the average cost per patient of the entire care pathway for drug susceptible tuberculosis (DS-TB) was USD 324 for all facilities in Zimbabwe in 2018 (Chirenda et al., 2021). To which extent time-driven activity-based costing as a management tool to provide accurate cost estimations is open to discussion. What's more interesting is how the TB service delivery processes are coming to grips within Zimbabwe. In the event that it is used as a source of collective learning experience to find out where the trouble with the pricing mechanism lies, the story is unlike in kind, for example root cause analysis (Rizan et al., 2020).

To sum up, a clear distinction comes forward between a dynamic set against a static application of patient pathways, which is spot-on to where the difference between strategic and non-strategic patient pathways is situated (Gemmel et al., 2008; Matthias & Brown, 2016; Mould et al., 2010). Using pathways in a diagnostic way is equivalent to reporting performance outcome measures, only to give an account to the supervision and subsequently filed away (McCracken & Edwards, 2017). In that case, patient pathways are not managed as a cognitive productive apparatus. Pathways ought to be used interactively (e.g., to talk over what a statement truly stands for or what activities are due to be completed). In place of using a traffic light control system to track progress or deciding whether

abnormalities are high or low, it should lay the foundation for a healthy debate (Clark et al., 2014; Kelly et al., 2017). With the proviso that pathways are used interactively, it grows into a source of wisdom. In lieu of preserving the long-established operating procedures, pathways should be subject to change for an enhanced journey's end.

Healthcare organizations that seek to be innovative and act in response to patient needs are unable to make good use of waterfall pathways designed to steer clear of bolts from the blue. State of the art and personalized services cannot be reconciled with a methodology intended for mass screening and treatment. In this day and age, contradictions endure in terms of modern healthcare making headway by leveraging off the deep-rooted philosophy. That is not by any manner of means to say that health OM scholars are obliged to move away from conventional wisdom. It is firmly maintained that the opposing principles of the twofold patient pathway modes must exist in harmony despite different tenets and codes of belief. The modern and traditional outlook have got to co-evolve in order to achieve a balance of complementary contrary forces between heavily imposed discipline on one hand, and creative freedom on the other hand. The equilibrium of patient pathways serves as counterweights and pull in divergent directions, representing the balanced duality and interaction between the need for autonomy and authority.

2.6 Relating SDL and patient pathways

To the best of my knowledge, this is the first time the SDL and patient pathway literature has been systematically related with the specific conceptual goal of comparison by means of differentiating and integrating (MacInnis, 2011). Differentiation aids in the discernment of diverse elements and their unique characteristics, thereby facilitating the analysis and eventual integration of these elements into a unified whole. To integrate means looking at “*previously distinct pieces as similar, often in terms of a unified whole whose meaning is different from its constituent parts; to synthesize, amalgamate, or harmonize*” (MacInnis, 2011, p. 138). By juxtaposing these mutual reinforcing perspectives, the theoretical contribution aims to account for the interplay and potential synergies between SDL and patient pathway concepts.

In the realm of healthcare, where various actors (e.g., patients, next-of-kins, and physicians) form interconnected social networks, an ample view of the entire system becomes fundamental. Notably, scholars like Matthias and Brown (2016), McCracken and Edwards (2017), Mould et al. (2010), and Williams and Radnor (2022) have adeptly employed a whole systems approach to effectively communicate and map patient pathways. In contrast, most other reviewed health OM academics have adopted a reductionist approach, dissecting pathways into shorter routes (e.g., Improta et al., 2015; Murphy et al., 2019). The reductionist reasoning allows for pluralistic interpretations, treating extracted elements from the whole scope as a unified description of the phenomena. Nevertheless, it tends to overlook the intricate nature of healthcare, by primarily focusing on micro level perspectives (Wilhelm et al., 2020). While zooming in on specific subpathways yields detailed process maps, these

representations risk oversimplifying to the extent of misrepresentation (Lusch & Vargo, 2014; Mould et al., 2010). The underlying challenge lies in the understanding that "*the whole is greater than the sum of its parts*" as famously stated by Aristotle. This concept emphasizes the importance of viewing the healthcare system holistically rather than isolating individual components. By adopting a systemic viewpoint, a more profound understanding of the labyrinth interactions and mutuality that characterizes the ecosystem is acquired. Such an approach recognizes the significance of interconnectedness and underscores the need to study healthcare phenomena in their entirety, avoiding the pitfalls of mistaken beliefs.

A surgeon or a scalpel on their own accords could bring about sweeping statements and half-truths, provided that "*value creation involves the integration of multiple resources by multiple actors simultaneously or as part of an integrative process, in the context of structures*" (Lusch & Vargo, 2014, p. 180). An extended enterprise perspective "*zooms out to the second, third, and additional tiers of dyads and triads of actors and resources, a broader and more realistic perspective of the service exchange system emerges*" (Lusch & Vargo, 2014, p. 159). The long-term endeavor of holistic thinking facilitates the progression of patient pathways by focusing on how social and economic actors interdepend and collaborate in the long run within the health and social care ecosystem. Williams and Radnor (2022, p. 1136) attest to the validity of the approach in asserting that "*public services are not just organisations but are in fact systems and need to be governed as such*".

In order to delve into the multifariousness of the ecosystem, it becomes beneficial to deconstruct its aforementioned definition into integral elements (MacInnis, 2011). This endeavor aids in the analogical and analytical processes of intellectual reasoning, leading to logically valid insights into the inseparabilities and separabilities within the healthcare organism. Key concepts associated with service ecosystems, such as self-adjusting systems, resource-integrating actors, shared institutional logics, mutual value creation, and service exchange (Lusch & Vargo, 2014), will be scrutinized in this conceptual contribution. By critically examining these components, a more profound comprehension can be developed regarding the underlying dynamics that shape and drive the interactions within healthcare.

Table 1 provides a condensed selection of quotations from the literature. However, this section offers an overview rather than an exhaustive examination, ensuring that the broader context is not obscured by excessive details. While the table faithfully represents the literature, this segment presents a subjective analysis of the distinctions and similarities between the reviewed works. Table 1 demonstrates a compelling convergence of the notion of service ecosystems, frequently nested within larger ecosystems, seamlessly aligns with conclusions reached in the patient pathway literature, emphasizing the involvement of the broader public service system (Lusch & Vargo, 2014; Williams & Radnor, 2022). Williams and Radnor (2022) lucidly describe how patient pathways extend to encompass various domains (e.g., housing, education, and benefits, ultimately fostering the overall

well-being and independent living of patients and their next-of-kins). Similarly, Aarhus et al. (2019) underscore the importance of connecting local patient pathway arrangements to the larger whole, emphasizing the need for integration and continuity of care.

Table 1: See Appendix A for a full overview of the table relating SDL and patient pathways.

SDL	PATIENT PATHWAYS
<p>Larger service ecosystem <i>“Service ecosystems are, however, also often nested within or are part of another, larger service ecosystem”</i> (Lusch & Vargo, 2014, p. 163).</p>	<p>Wider public service system <i>“[...] can extend to the wider public service system (e.g. housing, education, benefits) which can assist the general well-being and independent living of patients and their relatives”</i> (Williams & Radnor, 2022, p. 1137).</p> <p><i>“[...] connect the local system to the larger whole</i> (Aarhus et al., 2019, p. 3). <i>“Proposition one [of the SERVICE framework] refers to public service organisations being part of complex service delivery systems [...] In the UK and elsewhere, there are continual calls for better joined-up healthcare services”</i> (Williams & Radnor, 2022, p. 1129).</p> <p><i>“The critical sensemaking perspective, introduced by Mills et al. [46] and elaborated further by Aaroma et al. [47], provides a framework for understanding how individuals make sense of their environments at a local level while acknowledging the societal context [...] Critical sensemaking positions the context as a link between dominant social values and individual action”</i> (Torseth & Adnanes, 2022, p. 3).</p> <p><i>“Crossover of care is a key element of patient care pathways, hence ‘thinking process’ provides an opportunity to picture individual processes, their connections and links with associated processes and how they fit into the whole care process”</i> (McCracken & Edwards, 2017, p. 10).</p> <p><i>“Frontline professionals are socially embedded in society –that is, they depend on the nested social arrangements that extend beyond their professional community[...] the autonomy perspective tends ‘not to consider the wider ecological context’”</i> (Wilhelm et al., 2020, p. 1192).</p>

A nuanced divergence arises when the role of public service organizations is considered. The SERVICE framework, as expounded by Williams and Radnor (2022), underscores the significance of public service organizations as integral components within complex service delivery systems. This aligns with the persistent calls for amore cohesive and integrated service provision, underlining the importance of smooth linkages between different aspects of patient pathways. The critical sensemaking perspective offers sharp knowledge into how individuals make sense of their environments while acknowledging the broader societal context (Torseth & Adnanes, 2022). This perspective resonates with the concept of nested social arrangements highlighted by Wilhelm et al. (2020), accentuates the interdependence of healthcare professionals with the wider ecological context beyond their professional community. Additionally, the notion of crossover of care, as discussed by McCracken and Edwards (2017), along with the thinking process approach, enables a visual representation of individual processes, their connections with one another, and their place within the entire care process. This echoes the idea of nested ecological units within the larger welfare context, as declared in the SDL service ecosystem definition (Lusch & Vargo, 2014).

2.6.1 Multilevel complexity in healthcare

The concept of layers of aggregation within patient pathways is an integral and fundamental aspect of the systems logic when applied to healthcare (Lusch & Vargo, 2014; Vargo & Lusch, 2017).

Pathways, which delineate the course individuals follow through the system, operate at multiple intertwined tiers, ranging from the micro (i.e., individual patient level), to the meso (i.e., organizational level), and macro (i.e., systemic level). This perspective emphasizes the interconnectedness and interdependencies between these levels, recognizing that an all-encompassing approach is indispensable for effective management and communication within patient pathways. At the individual level, patient pathways focus on the specific patient and their specific needs, to wit, diagnosis, treatment, and ongoing care provided to the patient within a particular setting. The micro level involves direct interactions between patients and healthcare professionals, considering contingency factors (e.g., shared decision-making, patient empowerment, and personalized care). As aptly illustrated by Feyrer et al. (2006, p. 92), the concept of a “*modular system with an increasing degree of detail*” characterizes the interwoven nature of the microscopic level interactions, ensuring that the care provided meets the unique needs, preferences, and goals of each patient.

Elevating the perspective to the meso level, patient pathways expand to encompass the organizational and institutional aspects of service provision (Vargo & Lusch, 2017). This level involves multiple organizations (e.g., hospitals, clinics, primary care practices, and community services) working together to provide coordinated care delivery. The community level focuses on the collaboration and information exchange between these entities to ensure smooth transitions along the pathway. Kelly et al. (2017, p. 541) demonstrates how patient journey mapping tools effectively aid in identifying practice issues and “*seek strategies at personal, professional, organisation, and system levels*”, accentuating the importance of effective communication and management within and between healthcare organizations.

At the macro level, patient pathways extend further to encompass the broader health regime and its policies, regulations, and funding mechanisms involved in governing the structures of healthcare (Lusch & Vargo, 2014; Vargo & Lusch, 2017). The macro level considers the systemic factors that influence the design, implementation, and outcomes of patient pathways (e.g., resource allocation, quality standards, and population health goals). Rizan et al. (2020) points out that resistance to change can manifest at various strata, including individual, organizational, and policy levels, highlighting the significance of addressing systemic challenges for effective patient pathway management. By giving preferentiality to a systemic view, the concept of layers of aggregation encourages healthcare organizations to consider the micro, meso, and macro levels simultaneously (Lusch & Vargo, 2014). This approach enables executives to surmount barriers existing at each tier and to formulate strategies and intervention that promote high-quality and efficient service provision. It acknowledges that patient pathways do not exist in isolation but are integral components of a larger ecosystem characterized by multiple actors, processes, and resources.

2.7 Summary

While existing research on patient pathways has been significantly influenced by principles from health OM and lean thinking, it becomes increasingly apparent that prior studies exhibit limitations that underscore the importance of undertaking this research endeavor. The prevailing trend in literature involves isolating individual topics for investigation without establishing linkages between them, such as exclusively delving into activity-based costing or the balanced scorecard (Wackers et al., 2021). Compartmentalized approaches pose challenges in healthcare settings where resources and mechanisms are interconnected, leading to potential erroneous assumptions regarding specific facets and their relationships to contextual variables (i.e., contingency factors). Concentrating solely on the calculation of costs per patient may inadvertently obscure other vital aspects concerning pathways. Similarly, a myopic focus on chronological sequences may inaccurately imply that the success of a clinic solely depends on a linear patient pathway approach (Torseth & Adnanes, 2022).

Williams & Radnor (2022, p. 1137) highlight the need for “*wider integration across the healthcare and social care system (network)*”, prompting a call for further investigation in this direction. They advocate for expanding research beyond individual journeys to encompass different levels of the system (e.g., organizations, networks, and diverse health and social care settings). In parallel, Frangeskou et al. (2020, p. 1194) accentuate the importance of developing “*a multidimensional and multilevel model of “process” management*”, a perspective somewhat present in health operations management literature but remains underexplored. Given the absence of a substantial body of literature to establish a consensus, a pragmatic approach is suggested to strike a balance between capturing complexity and avoiding cognitive overload during the analysis (Matthias & Brown, 2016). Furthermore, Matthias and Brown (2016) posit the prospect of conducting additional research pertaining to process development within hospital settings to acquire a broader perspective on the myriad of factors influencing patient care and hospital performance (e.g., the influence of pharmacy on the length of stay for non-elective inpatients).

The theoretical inquiry into the interplay between SDL and patient pathways not only underscores the complexity of health ecosystems but also beckons further scholarly exploration and progress. As previously noted by scholars in the field, there is a pronounced need to delve into more extensive integration within healthcare and social care systems, delve into multidimensional and multilevel models of process management, and empirically investigate these matters within real-world contexts. The prevailing patient pathway literature unequivocally underscores the imperativeness for a holistic approach to unravel the intricacies of healthcare systems. By embarking on these trajectories, this study aspires to make valuable contributions to the advancement of knowledge and comprehension regarding the mutual interdependence and ramifications of the systemic perspective, ultimately enhancing the delivery of healthcare services.

3.0 Methodology

The development of the research design was informed by the overarching research purpose, the specific research inquiries at hand, constraints related to time and resources, the selection criteria for informants, as well as sampling and data collection strategies (Clark et al., 2021). Effective decision-making in research design necessitates a deep understanding of the philosophical underpinnings of qualitative research. It is imperative that these philosophical foundations align with the researcher's own worldview and correspond to the research questions being addressed (Merriam & Tisdell, 2015). Ethical data collection within the research paradigm hinges on three foundational pillars: ontology, epistemology, and methodology. A philosophical positioning of the research requires addressing personal beliefs about “*the nature of reality*” (i.e., ontology), and “*the nature of knowledge*” (i.e., epistemology) (Merriam & Tisdell, 2015, p. 9). The methodology, in turn, is derived from assumptions about ontology and epistemology, known as “*the nature of systematic inquiry*” (Flick, 2018, p. 35).

An elucidation of the interconnections between ontology, epistemology, and methodology in the realm of applied social sciences can be facilitated through the examination of the chosen research issue. Accepting as true that “*the reality is socially constructed*” characterizes an interpretive approach to qualitative research (Merriam & Tisdell, 2015, p. 9). That is to say that there are multiple interpretations of a single event in favor of one observable reality only. Concepts (e.g., frozen activities or process orientation) are products of this social construction. Instead of passively seeking existing information, scholars actively engage in the construction of knowledge. Creswell and Poth (2016, p. 20) further detail this worldview whereby individuals “*develop subjective meanings of their experiences-meanings directed toward certain objects or things.*” Social constructivism is a term often used interchangeably with the epistemologist assumption of interpretivism, suggesting that subjective meanings are relative to historical, cultural, and social factors (Creswell & Poth, 2016; Merriam & Tisdell, 2015). Put differently, meanings are fluid rather than fixed in the cognitive processes.

3.1 Ontology and epistemology

The stark dichotomy between the two realms of knowledge finds eloquent expression in the words of Dilthey, as cited by Kalaga (2015, p. 103) who encapsulated it as follows: “*we explain (erklären) nature, we understand (verstehen) human life*”. This research is firmly grounded in the philosophical tradition of hermeneutics, a theoretical framework for interpretive comprehension that accentuates the significance of context and original intent (Patton, 2014, p. 136). Often termed “*the art of understanding*,” attaches known meanings to the obscure or unfamiliar (Kalaga, 2015, p. 1). In the 20th century, the interpretive philosophical thought took shape through two primary avenues, namely, Gadamer's universal understanding of hermeneutics, rooted in ontology, and Dilthey's exploration of the relationship between understanding and explanation as a method (Kalaga, 2015). Within the purview of this study, understanding is conceived as a state of existence rather than a form of

knowledge. Gadamer, influenced by his mentor Heidegger, is a leading proponent of hermeneutics' universality in contemporary discourse, providing an essential underpinning for the interpretation and elucidation of both scientific and non-scientific forms of knowledge (Kalaga, 2015).

Gadamer's hermeneutic philosophy significantly informs the philosophical underpinnings of this study, with discernible inspiration drawn from Heidegger's work, exploring the intersection of theory and practice in interpretation (Kalaga, 2015). Heidegger anchors philosophy in the ontological principle of being, focusing on the nature of phenomena (Van Manen, 2016). Central to Heidegger's (1996) philosophical discourse is the concept of human existence, emphasizing the uniqueness of the mode of being. From this standpoint, fundamental ontological questions regarding the true nature of reality and the origins of knowledge emerge from an initial, albeit nebulous, grasp of the research problem. Gadamer advances Heidegger's concept of preunderstanding, which pertains to the projection of potential meanings onto the text, hereby influencing the formation of research inquiries (Kalaga, 2015). These preconceptions are built upon one's inherent interpretive abilities.

In traversing the terrain of ontology and epistemology, understanding emanates from the investigator's horizon of meaning, defining their "*field of vision*" (Kalaga, 2015, p. 91). An illustration of this concept might involve the expectation, rooted in culturally established meanings, that physicians should wear white coats (Babich, 2017). Prejudices, central to Gadamer's hermeneutic philosophy, represent pre-judgments that underlie the foundation of preunderstanding (Babich, 2017). Prejudices signify the anticipation structure of human experience, exerting influence on the formation of preunderstanding (Gardner, 2010). Their presence serves as a fundamental hermeneutic cornerstone for understanding the realms of healthcare management and communication, as they are inextricably intertwined with the historical context, the ever-evolving horizon of meaning, and their enduring character (Gardner, 2010; Kalaga, 2015).

An examination of the influence of these philosophical views on the adopted research methodology reveals that the interpretive research employed in this study is shaped not only by the principles of social constructivism and hermeneutics but also by the paradigms of symbolic interactionism and phenomenology (Merriam & Tisdell, 2015). Symbolic interactionism delineates social reality as a web of interactions, while phenomenology delves into the manner in which individuals ascribe meaning grounded in their experiences (Van Manen, 2016). Symbols representing absent objects (e.g., a sample tube on the National Online Health Service Platform) enhance patients' journey by fostering independence. Symbolic interactionism rationalizes functional relationships and interpersonal perceptions at play, while hermeneutics offers a deeper insight into the process of sense-making (Van, 1990).

3.1.1 The hermeneutic circle

A closer examination of the process of intellectual capacity through the lens of Gadamer's concept of prejudice and the horizon of meaning, as elucidated by Kalaga (2015), unveils the unfolding of

interpretive understanding and the expansion of intellectual capacity. At the heart of this process lies the hermeneutic circle, a fundamental concept denoting the intricate relationship between a text as a unified entity and its constituent parts. In the words of Kalaga (2015, p. 19), "*a part is a reference to whole and vice versa*". In the realm of Gadamerian hermeneutics, this circular movement signifies a dynamic interplay between the interpreter's perspective and the perspective embedded within the text itself. This oscillation between prior comprehension and newfound insights creates a continuous and evolving dialogue, for example when engaging with a specific paragraph, one's knowledge is not only enriched but also refined, narrowing the focus on broad subject matter (Gardner, 2010). The essence of meaningful understanding arises from this harmonized discourse between the interpreter and the text (Kalaga, 2015). Thus, the application of the hermeneutic circle facilitates an iterative apprehension of how healthcare management is conceived, communicated, and attributed.

Before transforming textual content, observations, symbols, and expressions into meaningful understanding, several crucial considerations must be taken into account (Kalaga, 2015). Although commencing from the horizon of meaning does not imply the constriction of comprehension within its boundaries, it acknowledges that a text possesses its intrinsic authority and horizon (Gardner, 2010). The interpreter and the body of evidence must engage in a "*horizon fusion*", viz., an overlapping that encompasses both realms (Kalaga, 2015). For Gadamer, this metaphor encapsulates the essence of the act of understanding. In the hermeneutic process of grasping texts, it is imperative to set aside preconceived notions, thereby paving the way for authentic and profound conception.

3.2 Methodology: phenomenological paradigm

Creswell and Poth (2016) delineate five distinctive qualitative research designs: narrative, phenomenological, grounded theory, ethnography, and case study. These methodologies share core attributes, such as emphasizing meaning, purposeful sampling, inductive data analysis, and presenting richly descriptive findings as themes or categories (Merriam & Tisdell, 2015). The phenomenological approach adopted in this study introduces an additional dimension, seeking to apprehend the essential nature and underlying structures of healthcare management and communication. It employs theory to comprehend the data, engaging an inductive rationale (Merriam & Grenier, 2019). This approach delves into the experiences of patients and healthcare professionals based on their subjective reality, thus transcending the subjective-objective dichotomy and recognizing reality as perceived by the informants (Merriam & Grenier, 2019).

From a phenomenological standpoint, the central focus is on the lived experiences of informants and the significance they attribute to these experiences (Van Manen, 2016). A lived experience is how an informant "*experiences the phenomenon in the moment*" (Merriam & Grenier, 2019, p. 88). Informants convey thoughts, values, intentions, and feelings. Through the use of open-ended questions, detailed descriptions from patients, next-of-kin, and healthcare professionals are gathered (Larsen & Adu, 2021). Interpretive phenomenology posits that comprehending the phenomenon is pivotal, as Vagle

(2018, p. 16) elaborates, "*one key assumption of this particular phenomenological methodology is that the phenomenon manifests ontologically in particular situations and contexts.*" Therefore, manifestations of the phenomenon are understood through reconstructed interpretations.

According to phenomenological founder Husserl, conscious acts are inherently intentional (Babich, 2017). In Husserlian terms, the social milieu is replete with meaning, interwoven with expressive capacities. Similarly, hermeneutics revolves around the concept of "*intentio auctoris*", denoting authorial intention, such as the careful selection of words or symbols (Kalaga, 2015, p. 11).

Essentially, a meaningful phenomenon derives significance within its given context. The choice to investigate healthcare systems is predicated on the fact that these ecosystems represent an external objectification, a "*manifestation of human intentionality*" (Kuada, 2012, p. 88). Informants articulate the ideas underlying their journeys, thereby unveiling their inner world. Private experiences contribute to a collective understanding. Gadamer argued that those engaged in research seek to unearth profound actualities within an autonomous text (Van, 1990). However, the truth, in this context, should not be conflated with a positivist notion of absolute truth. Texts hold a multiplicity of meanings that extend beyond the grasp of informants (Larsen & Adu, 2021). The meaning derived from textual analysis can transcend informants' original intentions, introducing a limitation wherein verbal communication may fail to capture aspects discerned through direct observation or participation.

Phenomenological inquiry strives for objectivity, while hermeneutics envisions both investigators and participants as co-explorers (Dinkins, 2005; Flick, 2018). This philosophical contrast compels the phenomenological approach to scrutinize biases, preconceptions, and their relationship with the research theme before the initiation of data collection (Larsen & Adu, 2021). Subsequent to this introspective stage, researchers engage in "*epoche*" via suspension of judgment (Merriam & Grenier, 2019, p. 88). However, maintaining this impartial stance can be challenging, as complete detachment from preconceived notions may prove arduous (Larsen & Adu, 2021). A constructivist epistemology asserts that researchers actively construct the world, negating the existence of an objective reality (Flick, 2018). To secure access to patients and clinical environments at Oslo University Hospital (OUH), establishing connections with influential figures within the SINTEF Digital and UiO research communities proved instrumental. However, it is essential to acknowledge that interactions with gatekeepers can introduce potential threats to the validity of data collection processes (Flick, 2018). This is because the personal subjectivity, motives, and beliefs of these gatekeepers can exert an influence on the study, thereby posing a risk of biased or erroneous conclusions (Larsen & Adu, 2021).

Hermeneutical phenomenology constitutes an approach that transcends mere interpretive methodologies, as it conjoins the realms of phenomenology, pertaining to lived experiences, and hermeneutics, concerned with the interpretation of life's texts (Creswell & Poth, 2016; Van Manen, 2016). The transition to a hermeneutical approach occurs when it encompasses both interpretive and

descriptive facets, striving to convey genuine insights into the phenomenon at hand (Van, 1990). Texts, in this context, act as vehicles for unveiling lived experiences through the lens of interpretation, ultimately crafting a mental image within the reader's comprehension. The core mission of this interpretation is to unearth the true meaning inherent of patient pathways, encompassing signals related to well-being and the ensuing consequences. The hermeneutic paradigm adheres to an ideographic stance, concentrating its scrutiny on singular phenomena (Kuada, 2012).

3.3 Choice of research design

In crafting the research design, this study adopts an exploratory approach that strategically employs distinct research methodologies for personnel and patients as a means to fulfill its overarching research objectives. To enhance the methodological rigor of this study, a convenience sample is drawn from actors situated within the Southern and Eastern Norway health region, and patients diagnosed with nervous system disorders as per the ICD11 classification system (Clark et al., 2021; World Health Organization, 2022). The ICD11 system categorizes conditions that are either directly related to or have a substantial impact on the nervous system, which encompasses ailments (i.e., kidney cancer and MS). The choice of these conditions is underpinned by their inherent variability in clinical manifestations and neurological implications, rendering them ideal candidates for the investigation of a wide spectrum of patient experiences. Both kidney cancer and MS patients necessitate intricate, multidisciplinary care and play an active role in the management of their conditions due to the inherent complexity of these diseases (Cherif et al., 2020). While the study's primary focus revolves around healthcare management and communication, it is essential to recognize that these selected medical conditions serve as the backdrop against which the service provision is examined and analyzed. This study's uniqueness primarily resides in its examination of patient pathways, ultimately seeking to evaluate the applicability of Service-Dominant Logic within this dynamic context. The research methodology for this study encompasses two distinct but interconnected phases:

1. Structured in-depth interviews with healthcare professionals
2. Longitudinal mapping of patient journeys

3.3.1 Small-scale in-depth interviews

The adoption of structured in-depth interviews as a research design choice has been substantiated by a body of literature, attesting to its efficacy in generating meaningful data within the context of healthcare investigations (Bernacki et al., 2021; de Bont et al., 2016; Frangeskou et al., 2020; Kelly et al., 2017; Matthias & Brown, 2016; McCracken & Edwards, 2017; Torseth & Adnanes, 2022; Williams & Radnor, 2022; Aarhus et al., 2019). In-depth interviews, as a methodological format, afford a concentrated and systematic approach to information collection, facilitating a profound exploration of healthcare professionals' perspectives and experiences (Merriam & Tisdell, 2015). The structured nature of these interviews imparts a well-defined framework for directing the discourse while preserving the participants' liberty to articulate their thoughts and insights without constraints.

Flick (2018) further endorses the significance of small-scale, in-depth investigations in unraveling the intricacies of healthcare workers' experiences. Delving deeply into the perspectives and experiences of a selected cohort of N=5-10 professionals within the Southern and Eastern Norway health region offers insight into their needs, challenges, and aspirations within the ecosystem. This methodology aptly accommodates a multifaceted perspective, encompassing the viewpoints of diverse actors entangled in the service provision (e.g., general practitioners (GPs) to specialists, practice consultants, controllers, and coordinators). Nonetheless, it is imperative to acknowledge that a small and opportunistic sample size can be susceptible to bias and might not warrant broad generalization to diverse populations or contexts (Clark et al., 2021). Consequently, the findings may exhibit a more exploratory character, which may limit their applicability in the context of evidence-based decision-making.

Nonetheless, the focal point on individual standpoints within the purview of small-scale in-depth interviews has the potential to inadvertently divert attention from the overarching structural and systemic challenges embedded within the system (Merriam & Tisdell, 2015). While these interviews undoubtedly present a valuable contribution to the understanding of healthcare professionals' experiences, they may inadvertently fall short of capturing the intricate interplay of multifarious factors that influence the service provision and the broader determinants of public health.

Notwithstanding these limitations, in-depth interviews persist as a paramount qualitative research design, delivering a concentrated and sequential source of insights into the lived experiences and perspectives of healthcare professionals (Merriam & Tisdell, 2015). It is incumbent upon the researcher to reflect on these constraints and supplement the methodological approach with a longitudinal mapping component to engender a holistic comprehension of the service provision.

3.3.2 Longitudinal engagement

Under the guidance of the Pathway Project Manager, patient journey mapping occurred longitudinally. The process of devising metrics, the investigation of appropriate reporting structures, and the harmonious integration of data derived from heterogeneous sources were tailored to conform with the specific objectives delineated within the ambit of the thesis, specifically in the setting of Electronic Health Records (EHR), Patient Administrative Systems (PAS), and Health Registries (M1). In a collaborative partnership with a distinguished research scientist affiliated with SINTEF Digital, the study aspired to encompass a sample size within the range of N = 5-10 patients who had been diagnosed with conditions affecting the nervous system. The data collection period extended over 2-4 months, during which these patients would chronicle their experiences. Establishing an enduring, trust-based rapport with the participants was of paramount importance to ensure research integrity (Flick, 2018). It is imperative to acknowledge that longitudinal studies grapple with attritional challenges, which can cast a shadow on their external validity (Flick, 2018). Withdrawal of patients from the study or their unavailability for follow-up can inevitably lead to a reduction in sample size and the potential introduction of bias into the findings. The passage of time can also lead to decreased

patient interest and motivation, potentially resulting in incomplete or unreliable data. Therefore, the inclusion of patients' next-of-kin and their treating physicians, who underwent interviews and supported patients in documenting their patient journey, assumes paramount significance.

Longitudinal studies have soared in prominence within the realm of social sciences, primarily due to their instrumental role in informing policy decisions and catalyzing healthcare transformation, as highlighted by Flick (2018). They serve as conduits for obtaining a holistic view of trends, patterns, and patient trajectories spanning extended timeframes. The crux of the matter is that patient journeys, particularly in the context of chronic conditions, frequently unfold over the course of a lifetime. Assessing them through intermittent snapshots may fall short of capturing the full spectrum of the experience. Engaging in the longitudinal collection of data from patients grappling with neurological conditions affords an understanding of the multifaceted determinants impacting health outcomes (e.g., genetic, environmental, social, and behavioral factors). These insights hold a significant sway in the realm of policymaking, proffering evidence-based information concerning the enduring consequences of adopting a systemic perspective.

3.4 Design of interview guides and diary

Prior to processing personal data, explicit permission was obtained to conduct the research through the Norwegian Agency for Shared Services in Education and Research (Sikt). Personal data is “*any information that can be linked to a person*», for instance e-mail address, a person’s voice, age, or even combinations of data (Norwegian Agency for Shared Services in Education and Research, 2022). Processing encompasses a wide range of activities, from collecting and registering data to arranging, analyzing, transferring, storing, publishing, and archiving it. After conducting a thorough assessment of data management and privacy protections, both the student and INN University were included as project employees and data processors within SINTEF's existing data management plan. This assimilation didn't necessitate the submission of a new notification form, as only minor adjustments were made to the interview guides and informational letters.

At the time of revising the interview guides, the Norwegian Regional Committees for Medical and Health Research Ethics (REK, 2022) provided their approval for conducting the study. With the granted permission from REK, the study advanced with confidence, allowing for the ethical and responsible conduct of interviews and data collection. The preservation of confidentiality is of paramount concern in qualitative research, particularly in the context of a longitudinal exploration of an individual's state of well-being, as advised by Flick (2018). Participants have legitimate reasons for preferring not to be identified due to their personal circumstances, which presents a specific challenge in longitudinal studies where extensive in-depth data about individual participants is collected over time. Respecting and safeguarding participant confidentiality is paramount in maintaining trust and ethical integrity (Flick, 2018). Safety measures (e.g., using pseudonyms and codes to protect participant identities) were implemented to mitigate this concern. Robust data management and

storage protocols at UiO's TSD platform were considered and implemented to safeguard the security and anonymity of participants' sensitive information.

The interview guides underwent adaptations to elicit descriptions directly pertinent to the research issue. The in-depth interview guide for healthcare professionals was designed to begin with broader, open-ended questions, allowing participants to freely express their thoughts. As the interviews progressed, the guide gradually moved to more specific and focused questions (Flick, 2018). This sequential technique allowed for a deeper exploration of particular systemic aspects, facilitating the extraction of detailed information within the Southern and Eastern Norway health region (e.g., the initial queries asked participants to elucidate the concept of patient pathways within their specific contexts). By commencing with this broad question, a diverse range of interpretations and perspectives concerning patient pathways was revealed. Subsequently, the interview guide incorporated probing questions (e.g., inquiring about the utilization of patient pathways in their respective departments).

The design of the in-depth interview guide draws inspiration from two main sources: the RCN-financed pre-project of 2018 and The Care Process Self Evaluation Tool (CPSET) (Halvorsrud & Skjuve, 2018; Vanhaecht et al., 2007). In accordance with the recommendations put forth by The European Pathway Association (2023), CPSET, initially conceived as a quantitative instrument in 2007, required adaptation and fine-tuning to suit the specific objectives of the study. The interview guide covers five essential aspects, namely the organization and orchestration of the care process, patient-centeredness, communication with patients and their families, inter-institutional collaboration within the realm of health and social services, and the surveillance and subsequent tracking of the care process. To align the interview guide with the study's overarching aim, dimensions pertinent to the external environmental factors, digitalization, and legislative aspects were thoughtfully integrated.

The formulation of the interview guides and diaries for the longitudinal mapping was profoundly influenced by the Customer Journey Analysis (CJA). This approach is rooted in the findings of Halvorsrud et al. (2016) and Halvorsrud and Kvale (2017), which emphasize the importance of understanding and improving service quality through the customer journey analysis. The interview guides were developed to capture touchpoints along the patient's journey, crafted to gather detailed information on the experiences, perceptions, and challenges faced by patients during different stages. The guides were structured in a manner consistent with CJA principles, thereby facilitating the discernment of critical junctures in the patient's journey and enabling the identification of potential challenges and areas ripe for improved service provision.

The diaries utilized in the longitudinal mapping were structured to elicit continuous data from the patients. These journals served as a dedicated platform for participants to chronicle their experiences, emotions, and reflections over an extended temporal span. The primary intent of encouraging patients to consistently document their healthcare encounters was to facilitate the real-time capture of shifts and evolving perspectives as they traversed the intricate ecosystem. This longitudinal approach was

instrumental in not only observing the dynamic evolution of patient experiences but also in discerning recurrent patterns and gaining profound insights into the multifaceted factors that influenced their perceptions throughout this intricate journey.

The configuration of the interview guides, coupled with the diary format employed in the longitudinal mapping study, aligns seamlessly with the distinctive attributes of phenomenology. Phenomenology places a profound emphasis on grasping the intricate tapestry of participants' lived experiences (Merriam & Grenier, 2019). In line with this paradigm, a series of interviews is conducted to attain a profound comprehension of the participants' experiences. Seidman (2006) introduced a three-phase structure for conducting profound phenomenological interviews, which closely parallels the approach taken in the longitudinal mapping. The initial phase of these interviews concentrates on exploring the informant's life history. By delving into the patient's background, personal context, and past experiences, a broader understanding emerges regarding how these factors influence the participant's current perceptions and behaviors.

In the second interview phase, equivalent to the self-completion diaries, the prominence shifts to exploring the specific details of the patient's journey (Seidman, 2006). This phase entails delving deeply into the intricacies of the participant's interactions and encounters within the system and relevant experiences pertaining to patient pathways. The goal is to capture the nuances of these experiences in a more contextualized manner. Finally, the debrief interview phase centers on understanding the meaning that the experiences hold for the participants (Seidman, 2006). By delving into the underlying motivations, beliefs, and emotions associated with these experiences, an accurate and intuitive intellectual capacity is gained into their impact on the lives of the patients. As commonly observed in phenomenological studies, this iterative process allows for the capture of changes, developments, and the evolving nature of the patient's journeys (Seidman, 2006). Ultimately, this approach results in a rich and meaningful understanding of the management and communication practices being investigated within the healthcare context.

4.0 Data collection and analysis method

Collaborating within an international project group comprised of prominent researchers with diverse linguistic backgrounds necessitated the implementation of a cross-language data collection strategy, incorporating both Norwegian and English (Flick, 2018). The potential language barrier between the English-speaking postdoctoral fellow and the informants posed a risk to data quality throughout the interview sessions, transcription, coding, and the subsequent reporting of findings (Flick, 2018). To mitigate this challenge, a pragmatic solution was employed. I conducted interviews with non-English-speaking informants, whereas the postdoctoral fellow took charge of interviews with English-speaking informants. It is noteworthy that there may be limitations associated with Norwegian informants conducting interviews in English, as they may have felt less comfortable articulating their experiences and thoughts in their second language.

Conversely, challenges exist with interviews conducted in Norwegian and then translated verbatim into English. To address concerns regarding translation accuracy and fidelity, a multilingual colleague of the postdoctoral fellow performed a back-translation of the interview guide, both in English and Norwegian, ensuring the quality of translation. Consistent with the guidance provided by Flick (2018), collaboration with another scientist necessitated a series of both online and in-person briefings before the commencement of interviews. These interactions were instrumental in establishing mutual understanding and provided an opportunity for team members to familiarize themselves with each other's interviewing styles. Additionally, two test interviews were conducted collaboratively using a provisional interview guide. These practice sessions served to hone interview skills and ensured a harmonious and unified approach during the actual interview sessions.

4.1 Customer Journey Analysis

The decision to use the CJA in the longitudinal mapping stems from its adaptability to a broader range of contexts beyond customer interactions (Halvorsrud et al., 2016). Although CJA is predominantly associated with customer experiences, this study leverages its application to chart real-life patient journeys. CJA's theoretical foundation introduces a critical concept, evident in healthcare, that a journey can encompass both voluntary and mandatory elements, let's say, an individual visits a doctor and subsequently receives a referral to a specialist (SINTEF, 2022). Halvorsrud et al. (2016) elucidates how CJA offers distinct advantages, setting it apart from other process-oriented methods. Firstly, it relies on a formalized definition of journeys and touchpoints, which encourage more precise description of journeys. Secondly, it facilitates the examination of individual service experiences in relation to intended service delivery, enabling meaningful comparisons. Lastly, CJA allows exploration of how service experiences evolve over time by capturing both concurrent and retrospective patient experiences (Halvorsrud et al., 2016).

Halvorsrud and Kvale (2017) delves deep into the five phases of the analysis, providing extensive guidelines, illustrative case studies, and practical lessons on the application of the analysis. Phases 1 and 2 are dedicated to planned patient pathways, a notably complex facet of the healthcare domain due to its intrinsic variability, with a few exceptions (e.g., scheduled hip operations). A fundamental concern arises regarding the existence of a predetermined patient trajectory. Even in cases where patient progressions for kidney cancer have been outlined, they often remain quite general, necessitating further refinement to align with the CJA framework. Phase 2 maintains its focus on the identification of relevant pathways as perceived by specialized healthcare service providers (Halvorsrud & Kvale, 2017). At this stage, an outside-in perspective is adopted, which entails conducting two workshops involving Senior Consultants in Urology, two secretaries from the admissions office, and one case manager (Halvorsrud, 2016). Furthermore, patient-facing materials (e.g., the care pathways for kidney cancer treatment), underwent examination (Helsedirektoratet, 2022).

Phases 3 through 5 are dedicated to capture and in-depth analyze the genuine patient journey (Halvorsrud & Kvale, 2017). Examining these phases yields a clearer view of the tasks entailed, for instance, between step 3.2 and 3.3, the recruitment process occurs, which includes interviews, diary distribution, and subsequent use of self-reporting methods (Halvorsrud & Kvale, 2017). To ensure the meticulous selection and recruitment of study participants, two Senior Consultants in Urology from OUH were involved in the ad hoc sampling, considering criteria, namely, referral source, language proficiency, digital competence, age range, capacity for long-term engagement, and the availability of supportive relatives (Clark et al., 2021).

At a critical juncture during the data collection phase, a noticeable deceleration in the recruitment of kidney cancer patients prompted an exploration of alternative avenues, including patients with neurological disorders. Direct data collection from MS patients was initiated through another Pathway team member – a Senior Consultant Neurologist at OUH and Professor at the Institute of Clinical Medicine at UiO in neurology. An analogous recruitment procedure for MS patients was implemented, accompanied by concurrent efforts to engage study participants through a dedicated Facebook group for MS patients. It is essential to acknowledge that this transition from kidney cancer to MS patients introduced a notable limitation to the study. The planned pathways for MS patients received less extensive scrutiny compared to those of kidney cancer patients. Consequently, the ability to conduct a direct comparison between planned pathways and actual journeys was hindered for MS patients. This constraint underscores the need for future research to thoroughly investigate the planned pathways of MS patients, facilitating a comparative analysis across various medical conditions.

From the initial cohort of eight recruited patients, equally divided between individuals diagnosed with kidney cancer and those with MS, it is noteworthy that only half of them successfully completed the longitudinal study by engaging in a start interview, maintaining diary loggings, and participating in a

debrief interview throughout the designated 2-4 month period. Furthermore, only two next-of-kin interviews and one interview with a treating physician were conducted as part of this study. Patients diagnosed with kidney cancer and MS exhibited similar dropout rates, which raised concerns regarding the feasibility and robustness of the research findings, as almost half of the participants either proved unable or unwilling to sustain their involvement. It is believed that clinical complications significantly contributed to their discontinuation from the longitudinal mapping. These complications appeared to impose substantial challenges and burdens on the patients, potentially obstructing their sustained engagement with the research.

This diminished completion rate has prompted concerns about the representativeness and external validity of the findings. The limited participant pool may not adequately encapsulate the diverse experiences and challenges encountered by a more expansive and heterogeneous patient population. Nonetheless, it is crucial to underline that the study's objective is not to conduct comparative analyses among patient journeys or make overarching generalizations. Instead, the longitudinal mapping approach is focused on delving deeply into the subjective interpretations and experiences of individual patients. By emphasizing the unique perspectives of each participant, the longitudinal study strives to achieve an understanding of how patients construct their journeys and how these interpretations mold their trajectory. Prioritizing individual voices and the meanings ascribed by patients to their passage contributes to a nuanced comprehension of healthcare management and communication.

4.2 Gioia methodology

Within the spectrum of analytical methodologies applicable to the scrutiny of the in-depth interviews, two predominant approaches come to the forefront: content analysis, which aims to discern instances pertinent to the research topic, and thematic analysis, wherein data patterns are discerned and subsequently coded in alignment with these patterns (Ward & Delamont, 2020). Given the research's focus on understanding how Service-Dominant Logic can enhance the management and communication of high-quality and efficient service provision, opting for content analysis would only partially align with the problem statement. Descriptive data obtained from seven in-depth interviews, four clinicians and three medical coordinators, was subject to ongoing analysis and coding (Gioia et al., 2013). The analytical process and data management were executed through the use of Excel, facilitating direct handling of data and coding. The review of datasets and identification of meaning patterns to reveal dimensions were executed in a predetermined sequence:

1. Transcription of interviews verbatim
2. Inductive analysis enjoying the Gioia methodology
3. Identification of higher-order themes

A substantial body of literature in the patient pathway domain has underscored the prevalence of thematic analysis (Anderson et al., 2014; Bernacki et al., 2021; Cherif et al., 2020; Kelly et al., 2017;

Ly et al., 2021; Williams & Radnor, 2022). Notably, the Gioia methodology appears to be generating a significant amount of interest, given its traceability across disciplines and its prominent position in qualitative patient pathways research (e.g., Hollebeek et al., 2019; Matthias & Brown, 2016; Wilhelm et al., 2020). The Eisenhardt method also enjoys recognition, yet it is designed for examining two or more cases or their replications to investigate a specific phenomenon, underpinned by post-positivist assumptions (Frangeskou et al., 2020; Langley & Abdallah, 2011; Matthias & Brown, 2016; McCracken & Edwards, 2017; Skalen et al., 2015; Wilhelm et al., 2020). Consistent with the constructivist worldview, the Gioia et al. (2013) methodology is derived from grounded theory and embraces interpretive standards. The analytic method is not only growing in popularity, but just as well sheds light on the theoretical kinship between content analysis and thematic analysis. Instead of focusing on comparing cases to draw generalizable conclusions, viz., the Eisenhardt methodology, the Gioia methodology centers around a select group of informants at a specific point of time by means of interviews (Langley & Abdallah, 2011).

Gioia et al. (2013) expounds a set of guidelines for the effective application of this methodology, ensuring adherence to the highest standards of qualitative rigor. Central to these guiding principles is the inception of thematic analysis, a process that often involves formulating more open-ended research questions in comparison to the approach advocated by Eisenhardt (Langley & Abdallah, 2011). An integral step in this method is the refinement of the interview guide to extract nuanced interpretations from healthcare professionals. This shift in focus directs attention towards comprehending the perspectives, experiences, and narratives of the informants, rather than rigidly pursuing a fixed set of objective facts (Langley & Abdallah, 2011). The interviews culminate in the creation of a narrative that illustrates the “what”, “how”, and “why” of healthcare management and communication, elucidating the intricate factors and dynamics underpinning their evolution. The rhetorical structure of the writing assumes paramount importance in the Gioia methodology, where the primary aim is the artful conveyance of the informants' stories (Langley & Abdallah, 2011). Through the medium of storytelling, the subject matter springs to life, establishing a profound connection with readers and promoting a deeper realization of the phenomenon under investigation.

Drawing inspiration from Gioia et al. (2013) guiding principles, data collection and analysis transpire in tandem, fostering an ongoing dialogue with the developing dataset (Gioia et al., 2013). In the first step, transcripts undergo open coding, where data is categorized to uncover lower-level meanings (Ward & Delamont, 2020). Up to 100 codes were considered representative samples of first-order concepts in this study. These codes were synthesized to reveal connections and relationships within the data (e.g., quotes emphasizing the transformation from care pathways for cancer treatment to holistic patient pathways, converged to create an imperative for a shift in healthcare institutions). This integrative approach to the dataset with a fresh perspective allowed for the discovery of original concepts (Gioia et al., 2013).

Upon completion of coding first-order categories, they were combined into themes characterized by a higher level of abstraction. Gioia et al. (2013) repeatedly maintains that themes naturally emerge from the dataset, overlooking the fact that ideas that appear in the in-depth interviews are constructed and tested in an iterative refinement process. Once the higher-order themes are in place, an even broader view is undertaken by creating overarching dimensions. This is what Gioia labels the data structure, namely, first-order concepts, second-order themes, and aggregate dimensions (Gioia et al., 2013). With the data structure in its finalized form, the theory construction process began, progressively crystallizing into a framework and a set of proposed definitions related to value co-creation in healthcare (Gioia et al., 2013).

To some extent, the thematic analysis of the in-depth interviews deviates from the recommended features of the Gioia methodology due to its predetermined application of SDL (Gioia et al., 2013). Ideally, greater reliance should be placed on the phenomenon of interest (in this case healthcare management and communication), and less on preexisting theories to maintain an unbiased perspective (i.e., not take into account prior research to a greater extent than what is required at a minimum). Gioia et al. (2013, p. 26) is in favor of “*initially consult[ing] with existing literature, with suspension of judgment about its conclusions to allow discovery of new insights*”. In essence, the analysis process should aim to minimize external influence and prioritize inductive exploration.

4.3 Validity, reliability, and ethical standards

In the realm of qualitative research, a critical emphasis lies on the requirement for “*theoretical sophistication and methodological rigour*” to render the results both trustworthy and practically applicable (Adams et al., 2014, p. 245). Embracing a constructivist worldview, the standards for rigorously conducted studies deal with how to ensure trustworthiness, derived from “*the researcher’s presence, the nature of the interaction between researcher and participants, the triangulation of data, the interpretation of perceptions, and rich, thick description*” (Merriam & Tisdell, 2015, pp. 191-192). The quality of interpretive qualitative research is often evaluated based on criteria related to validity and reliability (Merriam & Grenier, 2019). Ensuring validity and reliability in the study involves collecting, analyzing, and interpreting the data, as well as presenting the findings in an ethical manner (Merriam & Tisdell, 2015). Grounded in the constructivist philosophical foundations of this paradigm, specific areas that address these aspects are internal validity, external validity, and reliability. Alternatively, these concepts can be referred to as credibility, transferability, and dependability, respectively (Lincoln & Guba, 1985). Adherence to these rigorous standards establishes the quality of the study, thereby ensuring that the findings are not only relevant to real-world practices but also significantly contribute to the advancement of knowledge within the field.

4.3.1 Internal validity

Internal validity, defined as “*the extent to which research findings are credible*” (Merriam & Tisdell, 2015, p. 265), raises fundamental concerns concerning longitudinal patient journey mapping and

structured, in-depth interviews. These questions revolve around whether the findings align with reality and whether the measurements accurately capture the intended aspects. To bolster the internal validity, a research protocol was designed to govern the data collection process, encompassing aspects (e.g., participant recruitment, informed consent procedures, interview guides, and diaries). To further enhance the credibility of the research findings, an inclusive sampling strategy was adopted during the study, expanding beyond kidney cancer patients to encompass individuals with MS (Merriam & Grenier, 2019). While this broader representation allowed for the exploration of variations within the data, there remained the potential for bias, as more resourceful and digitally adept patients with surplus energy might have been disproportionately inclined to participate. In order to ameliorate the potential for participant selection bias, a set of rigorous recruitment guidelines were delineated to ensure the sample's alignment with the demographic characteristics of the target population. Nonetheless, it is imperative to recognize that convenience sampling strategies are intrinsically fraught with challenges when it comes to attaining a sample that can be deemed fully representative (Clark et al., 2021).

Carefully crafted informative letters, along with a consent form, were systematically prepared and disseminated to all research participants (i.e., patients, next-of-kins, treating physicians, and healthcare professionals). This document expounded upon the project's objectives, delineated the roles of those conducting the study, outlined the nature of participation, elucidated the rationale for their involvement, presented an account of potential disadvantages related to participation, highlighted their rights as participants, and offered a detailed confidentiality statement to ensure the safeguarding of their personal information. Such a rigorous approach to data collection was pivotal in ensuring transparency, ethical compliance, and a lucid comprehension of the study's objectives by all actors (Merriam & Grenier, 2019).

The credibility of the research findings ultimately hinges upon the adeptness of interpreting participants' perceptions in a sensitive and contextually attuned manner (Merriam & Grenier, 2019). A dual-pronged data analysis approach (i.e., Gioia methodology and CJA) was employed to yield rich, vivid descriptions that effectively captured the essence of participants' experiences. This approach immersed readers in the data and facilitated a profound understanding of the intricacies of the healthcare environment. Lastly, peer debriefing sessions conducted after the interview sessions were an essential step to enhance the internal validity by inviting external perspectives and critical feedback. These practices ensured the research's credibility and the trustworthiness of the findings, contributing to a more substantial study.

4.3.2 Reliability

Another critical factor in ensuring internal validity pertains to the reliability of the data obtained, referred to as “*the extent to which there is consistency in the findings*” by Merriam and Tisdell (2015, p. 265). To uphold this consistency, validated interview guides were systematically for both the

longitudinal mapping and structured in-depth interviews (Halvorsrud & Kvale, 2017; Halvorsrud et al., 2016; Halvorsrud & Skjuve, 2018; Vanhaecht et al., 2007). This ensured a standardized data collection process, minimizing the impact of subjectivity. This methodological choice not only fortified the internal validity of the research but also cultivated an environment of trust with the participants, ultimately enhancing the reliability of the study (Merriam & Grenier, 2019; Merriam & Tisdell, 2015).

Sustaining a continual and robust presence during the study emerged as a focal factor. This profound involvement played a vital role in establishing rapport with participants, fostering transparency, and facilitating genuine interactions. The deliberate creation of an enabling research environment placed specific emphasis on fostering rapport with the study's participants. This method, distinguished by its comfortable and open setting, not only promoted candid and precise responses but also, consequently, bolstered the reliability of the gathered data. Addressing the needs and apprehensions of participants cultivated a collaborative relationship, thereby significantly elevating the quality and authenticity of the research findings.

Safeguarding the reliability of data collection during the extended patient journey mapping process held paramount significance. This was especially critical due to the collaborative aspect of data collection, which involved research scientists at SINTEF (Merriam & Grenier, 2019; Merriam & Tisdell, 2015). The participation of other research scientists added an additional layer of expertise in maintaining consistency and quality control, thereby enhancing the overall reliability of the study. Longitudinal studies require the continuous tracking and documentation of patient experiences, decisions, and outcomes at multiple intervals. Upholding methodological rigor in data collection over the entire duration of longitudinal mapping was imperative to ensure that the findings accurately captured authentic changes and evolving patterns in patient experiences over time.

4.3.3 External validity

External validity is defined as “*the extent to where the findings of a qualitative study can be generalized or transferred to other situations*” (Merriam & Tisdell, 2015, p. 265). Generalization is not attainable, nor a goal, given the limited sample size of seven healthcare professionals and four patients that completed the study (Clark et al., 2021). Instead, the concept of transferability was embraced, recognizing that qualitative research can contribute to the broader body of knowledge while respecting the nuances and uniqueness of individual cases. Furthermore, it's imperative to heed the guidance of Flick (2018) and Merriam and Tisdell (2015) concerning the significance of contextual factors in qualitative studies. It emphasizes that the findings in this study are inherently bound to the specific Southern and Eastern Norway health region. Replicating the study, even under the same researcher, following identical procedures, within the same context, and involving the same participants, would still yield results influenced by the distinctive contextual elements. Thus, it is

crucial to acknowledge the inextricable link between context and research outcomes (Flick, 2018; Merriam & Grenier, 2019).

The results outlined in this study pertain specifically to the patient pathways associated with kidney cancer and multiple sclerosis. While kidney cancer and MS patients exhibit variations in disease courses, both groups share the commonality of a slight reduction in life expectancy. It is noteworthy that MS represents a chronic neurological condition, whereas kidney cancer generally boasts a relatively high survival rate. The study's focus is primarily on pathways associated with medical conditions requiring long-term ambulatory care and multidisciplinary approaches, in contrast to the acute care provided for inpatients in a hospital setting. The applicability of these findings may extend to other medical diagnoses characterized by diverse care processes tailored to individual patients (i.e., provide valuable knowledge with broader implications for various diagnoses characterized by heterogeneous care processes).

4.3.4 Triangulation

To ensure robust internal validity and reliability, a principal strategy applied is triangulation, a method entailing the utilization of multiple theories, researchers, data sources, or approaches to corroborate preliminary finding (Denzin, 1970; Flick, 2018). Working in an interdisciplinary research team enhances credibility owing to the confirmation of findings across interviewers, observers, and investigators. For the in-depth interviews, the moderator role, and observer and note-takings role were pre-assigned. In the case of the longitudinal study, a team of three researchers actively participated in data collection. While this approach improves the quality of conclusions to some extent, there is no guarantee of improvement in the absence of ongoing collaboration during data processing and analysis of this undertaking. As noted by Merriam and Grenier (2019), investigator triangulation involves both collaborative data collection *and* analysis. However, the application of triangulation extends beyond this by means of theoretical combination of two literature streams, allowing for the mitigation of potential biases and the enrichment of the interpretation of findings.

While a mixed-method approach was not employed, triangulation was further realized by employing two distinct qualitative methodologies (i.e., in-depth interviews and longitudinal inquiry) enabling comparison and cross-verification of information from diverse viewpoints. The utilization of multiple data sources in the longitudinal mapping (i.e., patient-facing materials, workshops with personnel, self-completions diaries, and interviews with next-of-kins, treating physicians, and patients themselves) mitigated the risk of systematic or methodological error that stems from relying solely on a single source (Flick, 2018). Through this multi-faceted examination of healthcare management and communication, a more accurate understanding of the phenomenon was attained.

Deetz (1996, p. 194) presents a critical discourse regarding the "*dream of triangulation*" asserting its potential disconnection from the realities of interpretive research, particularly in the interpretivist domain. He posits that while triangulation aims to explore the same phenomena from multiple vantage

points to enhance validity, its full realization may elude interpretive researchers. These scholars' subjective interpretations are inevitably colored by their distinct life experiences, worldviews, and contextual peculiarities, resulting in divergent perspectives on the very same phenomena. Consequently, the ideal of achieving a complete convergence of viewpoints through triangulation may appear unattainable, given the inherent subjectivity intrinsic to human experiences (Deetz, 1996). Instead of pursuing an illusory unity of perspectives, interpretivist methodologies acknowledge the value of embracing the richness of multiple viewpoints (i.e., each interpretation serves to contribute to a more nuanced and holistic depiction). By recognizing and engaging with diverse views, interpretive research stands poised to enhance its findings and provide a nuanced depiction of the intricate social phenomena. Deetz's (1996) standpoint underscores the significance of reflexivity and transparency concerning interpretive stances. The acknowledgment of subjectivity and the appreciation of the distinct rationales underlying various interpretations can foster fruitful dialogues and bolster the depth of comprehension (Ward & Delamont, 2020).

Employing three out of four categories of triangulation presents a promising strategy for mitigating biases and establishing robust internal validity and reliability (Kuada, 2012). The fusion of diverse theoretical perspectives and heterogeneous data sources constructs a sturdy framework for validating and corroborating research outcomes. Even in the face of potential disparities or contradictions within the data, a thorough examination of these inconsistencies is not to be evaded (Kuada, 2012).

Uncovering the underlying causes of such disparities can unveil novel avenues for exploration, thus expanding the depth of research findings. Though the process of triplex triangulation may not perfectly align with interpretivist research, necessitating planning and execution, the resultant wealth of evidence and the heightened validity of the study outweigh the challenges. Recognizing and embracing varied perspectives can indeed enrich the interpretive process and lead to a profound grasp of the intricacies within healthcare management and communication (Deetz, 1996). In the context of interpretivist research, triangulation can be perceived as an ongoing and dynamic dialogue, one that embraces subjectivity and enhances the research endeavor. The adoption of this approach facilitated the derivation of well-informed conclusions and meaningful contributions to the field of study.

5.0 Results

Chapter five offers a thorough examination of the significance of the systemic perspective within the domain of healthcare management and communication, perfectly aligned with the problem statement. The extensive analysis draws exclusively from data garnered through in-depth interviews with healthcare professionals and the longitudinal tracking of patient experiences. By intentionally abstaining from an overreliance on pre-existing literature and the confines of an analytical framework, this approach yields an objective and unadulterated assessment of the tangible challenges and potential breakthroughs that manifest within the service provision.

5.1 Inductive thematical analysis

Coordinator #1 succinctly encapsulates a pivotal shift in healthcare policy by articulating:

“The status there now is that the current Health Minister has said that they want to move away from care pathways for cancer treatment thinking and to think about holistic patient pathways and forms of interaction - that is, holistic patient pathways”.

Conversations with healthcare professionals reveal the multitude of terminologies employed to encapsulate the notion of patient pathways (e.g., treatment patient pathways, clinical pathways, standardized pathways, patient journeys, care pathways for cancer treatment, interaction pathways, fixed pathways, and holistic patient pathways). This rich tapestry of terms reflects a discernible evolution of focus, shifting from a disease-centric perspective towards a more encompassing and holistic outlook. This shift is notably championed by the current Minister of Health and Care Services, Ingvild Kjerkol. Over time, the exigency to address a gamut of intricate patient pathways has emerged, and the efficacy of using care pathways design to address these complexities, beyond the initial phases of cancer treatment, has been called into question. Clinician #1 elaborates:

“I’m not willing to take a stand in the one way or the other, but it might be, I think they’re gonna change it [care pathways for cancer treatment] to patient pathways or interaction pathway, and of course then care pathways for cancer treatment might get it smaller definition than what patient pathway is in my head”.

As per the insights of clinicians and coordinators, care pathways for cancer treatment, initially conceived to navigate the labyrinth of interactions and logistical challenges faced by cancer patients, have themselves undergone a transformative journey. The current focus now centers on an all-encompassing approach that contains diverse conditions and sophisticated interactions. The concept of direct involvement and communication between entities (i.e., interaction pathways) has gained prominence. However, there is a consensus among these professionals that the central emphasis should be placed on holistic patient pathways. While it is doubtful that care pathways for cancer treatment will be entirely phased out, it is expected that they may undergo a name change and be integrated into

the broader scope of holistic patient pathways designed specifically for chronically ill patients. Clinician #2 reinforces the need for this shift by asserting, "*The numbers speak louder than the disease sometimes*".

The concept of discussing treatment cycles with the sample of healthcare professionals has found applicability in specific contexts. With the imminent launch of the National Health and Hospital Plan, set to underscore the significance of coordination and interactions within the ecosystems, a paradigm shift is evident. Titled the *National Health and Coordination Plan*, the focus no longer resides solely within the confines of specialized healthcare services. Instead, the model envisions a full panorama. Still, as described by one medical coordinator, a hospital department specializing in heart surgery must adeptly portray the internal discernments of the patient pathway. This involves dissecting it into visible touchpoints and elucidating the specific role each element plays within the overarching scheme. Nonetheless, the coordinator underlines that a patient's journey extends beyond the confines of a cardiac surgery episode, necessitating its integration into the broader pathway agenda.

Accordingly, it becomes imperative for each healthcare professional to discern their responsibilities within this expansive framework. Clinician #1 aptly summarizes this sentiment by noting, "*A patient is not a parcel, therefore care pathways for cancer treatment isn't a very good way of describing it*".

According to this clinician, the term care pathways for cancer treatment falls short in accurately describing the complex nature of patient journeys. A patient cannot be likened to a mere package, and hence, a more fitting philosophy is warranted. This sentiment underscores the evolving discourse within the healthcare landscape regarding the terminologies used to define patient pathways.

Streamline the patient experience

According to the medical coordinators that were interviewed, there is almost complete unanimity regarding the need to standardize pathways to ensure equal access to healthcare. Clinician #2 accentuated that, "*What needs to be standardized is that everyone gets the same right to equal health care*". Coordinators specifically point out that standardization yields multifaceted benefits, such as improved quality and safety of patient care, saves time for personnel, and optimizes resource allocation. As Coordinator #2 succinctly put it, "*It's easier when it's fixed*". Standardized patient pathways are in the structured interviews described as organized sequences of patient care activities and information sharing that bring clarity to the patient's journey. These pathways delineate the functions of personnel, procedures documentation, and collaboration during patient encounters. Additionally, they enable workforces to utilize their expertise efficiently, fostering a cost-effective division of labor between primary and secondary care. Properly designed pathways prevent the duplication of tasks between hospitals, municipal health services, and GPs, ensuring that responsibilities are appropriately distributed among different entities. The discourse subsequently ventures into reflecting upon which illnesses should be homogenized. When the clinicians contemplate patient pathway standardization for patients dealing with conditions like depression, wherein a

predefined number of treatment sessions is typically stipulated, they express reservations about rigid standardization. Within mental health, a uniform approach carries the potential risk of neglecting individualized requirements. Clinician #1 notes, *"If you standardize, if you make everything, if you try to put everything into a box - half of my patients won't fit into any box. So, as a GP I work around boxes and with lots of boxes, and that's why that's difficult"*.

While there may be certain shared attributes among patients grappling with depression, it is crucial to recognize the substantial disparities that persist. Prescribing a one-size-fits-all treatment regimen could potentially confine patients to a predetermined therapeutic trajectory, neglecting the nuances of their individual progress. A judicious and selective approach must be adopted when considering which elements are amenable to standardization. While specific routines and procedural aspects may be standardized, the interview objects emphasize the paramount significance of accommodating individualized needs. The medical coordinators who participated in the study shed light on their active engagement in workshops tailored to enrich collaboration and integrate a spectrum of approaches. Notably, one approach that resonates profoundly is service design, which assumes a central role in the establishment of effective frameworks for guiding patients along their journey. When healthcare professionals employ a service design approach in the development of patient pathways, their principal aim is to instill a sense of uniformity and consistency. Coordinator #1 points out, *"I've taken part in many types of workshops, so to - why? To develop collaboration and with different types of approach, for example, service design"*.

As articulated by the coordinator, this necessitates the establishment of uniform service encounters for patients, irrespective of their specific medical conditions. Whether a patient is grappling with breast cancer or contending with depression, the contextual determinants influencing their healthcare journey should exhibit a consistent character (e.g., reception, information dissemination, care delivery, and collaborative interactions). By engendering shared characteristics, a sense of familiarity is cultivated, ultimately optimizing the patient's experience. Interviewees emphasize that the granularity of these pathways can be adjusted to cater to the distinct requirements and preferences of diverse patient cohorts. In discerning the optimal level of abstraction and identifying the beneficiaries of these frameworks, critical considerations ensue, entailing an evaluation of who stands to gain from patient pathways and the breadth of their practical applicability.

Heightened patient involvement

According to the medical coordinators that were interviewed, a discernible trend has emerged, signaling the advent of active patient engagement in the decision-making process, particularly within primary healthcare settings. As Coordinator #1 points out, *"Some parts of the specialist healthcare service are probably still quite, what do you say, authoritarian. That the hospital decides and the patient agrees"*. Interviewees collectively acknowledge that treatment cannot proceed in the absence of explicit patient consent, a sentiment articulated by Clinician #1, *"You never send a referral*

anywhere without the patient's consent". Within specialized healthcare, there is a general agreement among the sampled professionals that a mutual accord between specialists and patients prevails. Patients, accordingly, possess the opportunity to express their approval, indicating their willingness to proceed with further medical interventions. This aligns with the shared opinion that treatment within primary healthcare hinges exclusively upon the patient's unequivocal consent, underscoring the importance of a robust doctor-patient compromise on the treatment plan. In the absence of patient consent, as they uniformly assert, no therapeutic measures are initiated (e.g., the procurement of medications or attendance at therapy sessions). While certain facets of secondary healthcare seemingly still adhere to an authoritarian decision-making approach, where decisions are devised by the hospital and sanctioned by the patient, a patient-centered paradigm is gradually gaining ascendancy. Patient education and informed consent are integral components of this shift. This paradigm, as emphasized by Coordinator #3, "*We should put the patient first*", further accentuating the prevailing sentiment that individuals are increasingly informed about their own medical conditions.

The concept of co-choice, as unanimously concurred among the sampled personnel, has recently taken root, involving an interactive conversational methodology that furnishes patients with impartial, accurate information to empower them in making autonomous decisions regarding their treatment. As noted by Clinician #2, "*We work with this slogan: what is important to you?*". Through this approach, patients are actively solicited to partake in the decision-making process, transforming them into proactive actors in their own journey. Furthermore, the momentum towards shared decision-making is growing within specialized services. The emphasis on patient-centered conversations and informed consent resonates strongly. Despite clinicians frequently acknowledging the challenge of time constraints, there is a concerted effort to allocate sufficient time for patient communication. While the specter of time limitations and the drive for efficient care delivery persist, clinicians underscore the gravity of clear agreements regarding forthcoming treatment steps (i.e., follow-up appointments and actions). Nurses or doctors typically initiate these discussions, delineating the next phases in the process. They might inquire, "Our policy dictates that we should proceed in this manner. Are you amenable to that?" or "Is this acceptable to you?" In line with the insights of healthcare professionals, the patient then, to varying degrees, is afforded the opportunity to voice their perspective. In this manner, the information presented to patients typically aligns with the internal documentation used within institutions or departments.

According to insights provided by clinical informants, it is essential to consider the involvement of family members and the provision of interpretation services for patients hailing from diverse cultural backgrounds as integral facets of the treatment cycle. The participation of next-of-kin is not subject to a standardized protocol but rather contingent upon the patient's preferences or needs. Clinicians underscore that while the presence of family members is encouraged, they are not vested with the authority to make treatment decisions on behalf of patients capable of providing informed consent.

Additionally, within the broader framework of patient involvement, addressing the needs of patients from diverse cultural and linguistic contexts is of paramount importance. The availability of effective interpretation services, as suggested by the healthcare professionals in the sample, is indispensable to ensure mutual understanding when communicating with patients who require such assistance.

Healthcare communities

In accordance with the insights derived from interviews, contemporary healthcare ecosystems epitomize an innovative care delivery archetype that underscores the pivotal role of robust partnerships and synergistic interactions among hospitals and their encompassing municipalities. These collaborations are institutionally codified through legal accords, as one coordinator highlights, mandating all involved entities to partake in a delineated and mutually endorsed cooperative framework. This framework is orchestrated to engender a symbiotic relationship between hospitals and municipalities, aiming to architect coherent patient trajectories. Accentuating the universality of patient-centric care, Coordinator #3 suggests, *“It might as well be me or you who were the patient”*.

The nexus forged within these ecosystems cultivates an environment conducive to candid communication and unfettered information exchange across diverse healthcare providers. This concerted approach, as noted by informants, serves as a conduit to ensure that essential patient information remains readily accessible to all pertinent actors, culminating in enhanced care quality and safety. In the spirit of patient-centricity, a guiding principle emphasized by the sample of healthcare professionals, the ecosystem is designed to cater to the bespoke exigencies of individual patients. Incorporating both primary care and specialized care providers, the healthcare framework adopts a multifaceted character, adept at furnishing customized services tailored to the nuanced requisites of each patient. Highlighting the diverse patient population served within this collaborative framework, Clinician #2 points out: *“Here we work with young MS patients in their 20s to almost 100-year-old Parkinson's patients”*.

Resource allocation and utilization are reported to be judiciously managed within collaborative ecosystems. Through the amalgamation of strategic planning and concerted coordination, healthcare providers can optimize resource deployment, ushering in more streamlined and efficient service offerings for patients. The structured platforms of regular meetings and deliberations intrinsic to healthcare ecosystems, exemplified by the likes of Meeting Place Oslo. As Coordinator #1 describes it, *“[Meeting place Oslo] is a meeting arena that we have developed where we particularly discuss cooperation in the medical service in the patient process between GPs and hospital doctors”*. This commitment to incessant improvement exemplifies the dedication of care communities towards heightening the caliber of care dispensed to patients.

Ensuring continuity of care and post-treatment follow-up

Within the discourse concerning collaborative dynamics across healthcare institutions, the nexus between hospitals and primary care stands out as pivotal (i.e., the municipality, GPs, community

nursing services, nursing homes, accident and emergency departments, and municipal acute inpatient units). A cogent unanimity among healthcare professionals accentuates the significance of inter-institutional collaboration for holistic pathways. Notably, informants underscore that attention to post-treatment care often becomes a secondary consideration, especially within surgical units that prioritize delivering uncompromised surgical interventions. Despite the brevity of a hospital visit, it represents merely a fractional segment of the complete disease trajectory that patients traverse. Coordinator #2 underscores the growing challenges in post-COVID care, noting, “*After covid the waitinglists have just rocketed*”.

Strategizing patient pathways necessitates a panoramic view encompassing the entirety of a patient's illness trajectory (i.e., commencing from pre-hospital care and extending into post-treatment follow-up). The endeavor, as per the insights shared by the interviewed healthcare professionals, mandates harmonizing the distinction between in-hospital treatments and the ensuing course of care beyond hospital premises. It is pivotal to appraise the holistic journey of patients confronting chronic ailments, acknowledging that the temporal phases of care warrant tailored approaches. A poignant example, as highlighted by Coordinator #2, emerges with cancer patients, for whom enduring side effects may manifest months or even years after the primary treatment. Notably, for patients necessitating long-term or lifelong care, the underpinning of holistic pathways proves instrumental in perpetuating care continuum and post-treatment vigilance. In this purview, meticulous scrutiny of the efficacy of the treatment regimen emerges as an indispensable facet. Coordinator #2 emphasizes the challenge, saying, “*You don't see anything but the next step*”.

As per the perspectives shared by the interviewees, intractable fragmentation within patient pathways entails the dearth of seamless coordination and harmonious exchange among actors, internal departments, and diverse systems integral to the service provision. Lamentably, the separation between clinicians and administrative personnel impedes collaborative discourse, stifling the resolution of issues. The resultant confluence of delays, miscommunication, and inefficiencies, as observed by the sample of healthcare professionals, engenders a disconnected patient journey. A distinct case in point arises where the intersection between healthcare providers and external entities (e.g., the Norwegian Labour and Welfare Administration) becomes a source of inefficiency, reflective of the disjuncture between communication conduits. This inadequacy ensnares the timely acquisition of crucial information and the orchestration of care collaboration with external bodies. Clinician #1 laments the challenges, stating, “*We work in all these grey zones*”.

The absence of coordination among distinct hospital wards accentuates the perils of fragmented patient pathways. According to the coordinators that were part of the study, in instances necessitating multi-faceted departmental engagement – think of patients navigating the complexities of concurrent brain tumor and dementia diagnoses – the lack of synchrony can breed disjointed care. The explicit reference to prolonged unattended referrals resonates as a stark manifestation of deficient post-

treatment monitoring mechanisms. This fragmentation, culminating in incohesive care, instigates delays and protracted waiting durations, potentially detrimentally impacting patient outcomes. Testimonies suggest that sluggish response times and the complexities of acquiring real-time updates accentuate the lopsidedness within patient pathways. Coordinator #2 adds a poignant note, stating, *“We don’t have the capacity to take everything. All the new, all the follow-ups. The math doesn’t add up”*.

Handover of responsibility in patient referrals

Clinician #1 describes patient pathways as, *“a way of trying to describe a patient’s maneuvers through the healthcare a system. From their first connection with their GP, what happens at the GP, what decisions are made with the patient and the GP that takes them onto referral into the hospital”*.

According to the medical coordinators who were interviewed, the seamless coordination of responsibility handover, both from primary care to specialized care and vice versa, emerges as an indispensable facet within the broader framework of patient pathways. The data collected from the in-depth interviews reveals that while collaboration is commendable, refining the clarity of communication and the comprehension surrounding the referral procedure remains imperative. The efficacy of collaboration, as per the informants, serves as the bedrock for ushering patients through transitions between diverse healthcare institutions. It is during these transitions that patients move within a mosaic of settings, and thus effective handovers are pivotal for ensuring coherence in their journey. Coordinator #3 highlights this by pointing out the significance of the free choice of hospitals scheme, *“There are the free treatment choice that will means that the patient can be referred to any hospital they want within the region, South-East Regional Health Authority”*.

The patient referral process stands as a nuanced terrain necessitating attention to guarantee the fluid transfer of responsibility and the precise dissemination of critical information. However, lurking within these transfers lies latent perils (e.g., mentions of communication lacunae, treatment continuity disruptions, and latent care delays). The paramountcy of patient safety and the orchestration of seamless care amid these junctures cannot be overemphasized, as stressed by Coordinator #1: *“Patient pathways between various institutions in the specialist healthcare service is, as far as I know, less described than patient progress between the primary healthcare service and the hospital”*. It is incumbent upon care systems, based on findings from the structured interviews, to address these challenges head-on through an amplification of collaboration, fortified communication channels, and assiduous documentation practices. The cardinal hallmark resides in the establishment of transparent pathways, for instance by well-defined conduits between primary care and specialized care realms. This warrants the delineation of roles and responsibilities for each entity implicated in the handover process, substantiated by information exchange facilitated by robust EHRs. Clinician #1 further emphasizes the potential risks of moving patients between primary healthcare and specialized

healthcare settings, by expressing, *“It’s an extreme sport to refer patients, but of course pathways help”*.

Coordinator #2 stresses the imperative for a systematic overhaul to enhance the follow-up procedures concerning referrals, citing instances where referrals have languished for protracted periods, in contravention of the prescribed ten-day timeframe. Notwithstanding the inherent challenges, healthcare providers, as elucidated in the interviews, demonstrate unwavering dedication to refining this process. They conduct periodic follow-ups at varying intervals (e.g., monthly, weekly, and daily checks). Healthcare providers embrace stringent safety measures and adhere closely to evidence-based guidelines during handover processes. According to insights gleaned from the interviews with medical coordinators, rectifying referral issues and fostering heightened collaboration and communication collectively transmute the handover of responsibilities into a safer, more streamlined, and patient-centric endeavor.

Quality standard for interdisciplinary collaboration

According to the medical coordinators that were interviewed, the imperative of disease-specific patient pathways pervades specialized hospital departments, constituting a quintessential framework. It remains incontrovertible that patient pathways cannot be universally standardized, particularly within primary care, where GPs navigate an expansive spectrum of diagnoses. Informants who are general practitioners, corroborate the labyrinthine challenges that beset the construction of patient pathways. Exemplified by the case of pediatric asthma, the focal point pivots from disease-oriented trajectories to the harmonization of collaboration across healthcare providers, regardless of diagnostic silos. The sample of professionals shares a common perspective that supports the establishment of a national benchmark. This benchmark would define the standardized procedures for collaboration between GPs and specialists, facilitating more efficient management and communication within the clinical milieu. As Clinician #2 aptly puts it: *“We do an awful lot of interdisciplinary work, which is part of our patient flow”*.

It merits attention that Oslo University Hospital, by virtue of its regional and national sway, interfaces extensively with diverse facilities. Interviewed coordinators entrenched within this hospital extol the tenor of this collaboration, attributing it with commendable quality. However, it is important to underscore that the quality standards underpinning this synergy remain nebulous, (i.e., lacking explicit articulation and institutionalization). To the awareness of the sampled personnel, a standardized quality framework that ensures fluid patient transitions and precludes any jeopardy to their well-being status remains a conspicuous void. This is particularly germane during the handovers between distinct entities within the specialized healthcare ambit. In this regard, it is evident from the structured in-depth interviews that the inclusive delineation of patient pathways between distinct institutions within the secondary care commands less prominence compared to patient pathways interlinking primary healthcare and hospitals. Coordinator #2 emphasizes this point by stating: *“The communication and*

collaboration with the other departments in the hospital is difficult, so I think the care pathways for cancer treatment makes the collaboration a lot easier because you have a main goal”.

According to one coordinator at the Oslo University Hospital, they find that deploying specialized personnel tasked with nurturing collaboration between hospitals and diverse entities could precipitate the inception of an all-encompassing quality standard. The crux of this standard, as the informants suggest, would be to stipulate the idealized patient pathways during instances necessitating transfers to or from the hospital. Notably, the existing framework accommodates the assimilation of such a standard. Findings from the interviews suggest that the South-Eastern Norway Regional Health Authority assumes an overreaching supervisory role, guiding specialized departments and collaborative undertakings. This supervisory authority holds the potential to assume a key function in endorsing and ensuring the application of this standard. Coordinator #1 adds, *“The primary healthcare and the GPs, they have to deal with all kinds of diagnoses, and to the extent that we have to standardize something for everyone, it is to the extent that we have standardized how we are to work together for everyone”.*

Concurrently, avenues could be explored to fabricate a national standard, engendering patient well-being during transitions across facilities, with a focus on collaboration and quality. This holistic standard, evidently, would encompass myriad dimensions, ranging from the selection of transportation modalities tailored to patients' specific circumstances and geographical nuances, to the seamless transmission of medical information. Informants indicate that this standard would equally champion patient welfare during transit, curtailing waiting times, and investigating alternative conveyance options. These multifaceted dimensions collectively form the fabric of a quality standard poised to metamorphose the scenery of patient pathways.

Interaction competence: a barrier to the quality of being large in scope

As per the sentiments shared by Coordinator #3, there is a prevalent perception that healthcare lags behind other industries in terms of technological advancement, with a statement echoing this belief, *“Healthcare is like 10 years behind the rest”.* The current state of technology falls short of meeting the needs and expectations of healthcare providers concerning efficiency and user-friendliness. Such perceptions can substantially impact workflow, communication, and ultimately patient care. Clinicians who are in direct contact with patients recurrently express concerns, primarily pertaining to their dissatisfaction with the functionality and efficacy of Dips, the electronic medical record system in use. Accordingly, Dips may not keep pace with the advancements in digital tools that could potentially enhance the service provision. Despite these perceived shortcomings, there is also recognition of progress and optimism, as exemplified by the anticipation of a new release of Dips. According to Coordinator #3, *“The systems are there. Most of them, at least”.*

This observation implies that both coordinators and clinicians are forward-thinking and optimistic regarding prospective developments. There exists a pervasive openness to adopting emerging

technologies as they become accessible, notwithstanding the gradual nature of the adoption process. Ultimately, the technological infrastructure required to facilitate seamless patient pathways, marked by reduced waiting times and minimal disruptions, appears to be at their disposal. Patients now possess the capability to remotely access healthcare services, diminishing the necessity for in-person appointments. Through the agency of shared patient data and electronic medical records, providers can work together to ensure that patients receive the right care at the right time, while reducing the risk of errors and delays. This proactive approach, according to Clinician #2, necessitates to have faith in the systems: *“You have to trust the systems”*

The findings derived from the in-depth interviews reveal a pervasive adoption of digital technology by personnel to optimize pathway management. This technological integration manifests through the utilization of specialized software for the purpose of information exchange, conducting video conferences, and fostering collaborative endeavors among professionals, thereby enhancing the efficacy of communication. Ongoing initiatives are geared towards the enhancement of documentation and the facilitation of information sharing via digital platforms. A pertinent illustration is evident in the proactive efforts of staff at Oslo University Hospital, who are actively engaged in streamlining their documentation procedures through the implementation of an e-handbook and the deployment of an e-learning platform, known as the Competence Bridge. This platform serves as an amalgamated information repository, fostering seamless data exchange between municipal health services and hospitals. While informal e-mail and telephone communication are extensively relied on to foster connections among healthcare professionals within and outside of hospitals, clinicians and coordinators prioritize facilitating collaboration in patient pathways by adhering to established agreements and guidelines. Coordinator #1 emphasizes this point by stating,

“We actually have a basic system in place, and we have many agreements on how we can do that. It is in a sense already designed, but on the implementation side, training and the competence that must be there is where we challenge”.

It is believed, according to informants, that the foremost inhibiting factor in the establishment of comprehensive patient pathways may not stem primarily from legal regulations or software-related constraints. Instead, it emanates from a perceived deficiency in interaction competence. Specifically, the challenge of disseminating expertise on designing patient pathways proves to be more complex. Personnel often struggle with questions such as *“whom should we consult?”* or *“where can we find the necessary resources?”* There are well-established agreements and communication channels (e.g., dialogue messages and electronic reporting to home care services) but the implementation of these resources presents the greater challenge rather than a lack of judicial support. In the words of Clinician #1, *“I don’t want to work in a monster digital journal”*

The challenge at hand cannot be exclusively or partially attributed to issues of system interoperability, characterized by the inefficacious communication of digital systems. While a minority of interviewees

advocate for the implementation of a unified record system, referred to as "*One citizen - one record*" as a remedy for all difficulties, the majority of participants hold a divergent perspective. They contend that their strength emanates from the availability of well-adapted tools tailored to their specific tasks. EHRs, in particular, possess the capacity to disseminate targeted information precisely when collaborative efforts are warranted. As an alternative, if advice is needed from a GP, direct input can be solicited. Clinicians place their reliance on meticulously crafted and concise documentation that they can readily share when the need arises in the context of a patient's specific condition. The fundamental system and formal agreements are in place to facilitate such endeavors, but the challenge lies in the effective implementation and sustained cultivation of the requisite training and expertise.

5.2 Longitudinal mapping of patient journeys

Phase 1 commenced by entailing an exploration endeavor, directed at attaining a sophisticated understanding of the inherent variability inherent within the designated patient pathway. This encompassed an analysis of parallel healthcare service providers, touchpoints, and interlinked patient journeys. A crucial element of this phase entailed participation in a multidisciplinary team (MDT) meeting hosted by the urology division, providing an opportunity to gain firsthand insights into the facets of the patient pathway. The observation of these proceedings not only offered experiential knowledge but also progressively honed the scope of the analysis, facilitating the identification of specific patient segments, behaviors, and other pertinent criteria.

The conducted workshops shed light on two distinct levels of planned pathways for kidney cancer treatment. Firstly, it was observed that the national guidelines outlining the care pathways for this condition were overly general, lacking the necessary specificity to be considered as precise representations of the expected patient courses (Helsedirektoratet, 2022). Secondly, a more tailored and thoroughly planned patient pathway was identified during the second workshop held at Aker Hospital. To visually depict the outcomes of these workshops, a diagram illustrating the kidney cancer pathways was developed. However, it should be noted that capturing all the intricate variations and nuances within a single chart proved to be a challenging task, primarily due to the diverse routes patients undertake to reach Aker Hospital. These divergent paths include different diagnostic procedures and referral routes, further complicating the task of creating a visual representation.

Moreover, the workshops offered the capacity to uncover concealed elements within the planned pathways for kidney cancer patients. They accentuated the disparities between the national guidelines and the more customized approach implemented at Aker Hospital. The resultant data structure diagram at a high-level served as a visual representation of the recognized pathway. However, the extensiveness of this representation across a wide spectrum was constrained due to the intricate and multifaceted nature of patient journeys. Nevertheless, this preliminary exploration and visual portrayal of the pathway laid the foundation for subsequent analysis and fine-tuning, with the objective of cultivating a more granular and precise comprehension of patient pathways, particularly in the context

of kidney cancer treatment. During the period of kidney cancer case examination, a realm encompassing intricate care services with diverse providers (e.g., GPs and radiologists), a higher level of abstraction was embraced to delve into the trajectory. This systematic approach accorded precedence to entities directly involved in specialized patient care, with the aim of achieving an all-encompassing understanding of the dynamics and interactions inherent in the ecosystem. The data generated during this phase plays an integral role in the ensuing phase 3, forming the groundwork for the formulation of efficient mapping procedure. These sequences of actions facilitate the continuous tracking and assessment of real patient journeys, aiding in the identification of areas necessitating enhancement and ensuring the consistent provision of high-quality care throughout the entire trajectory.

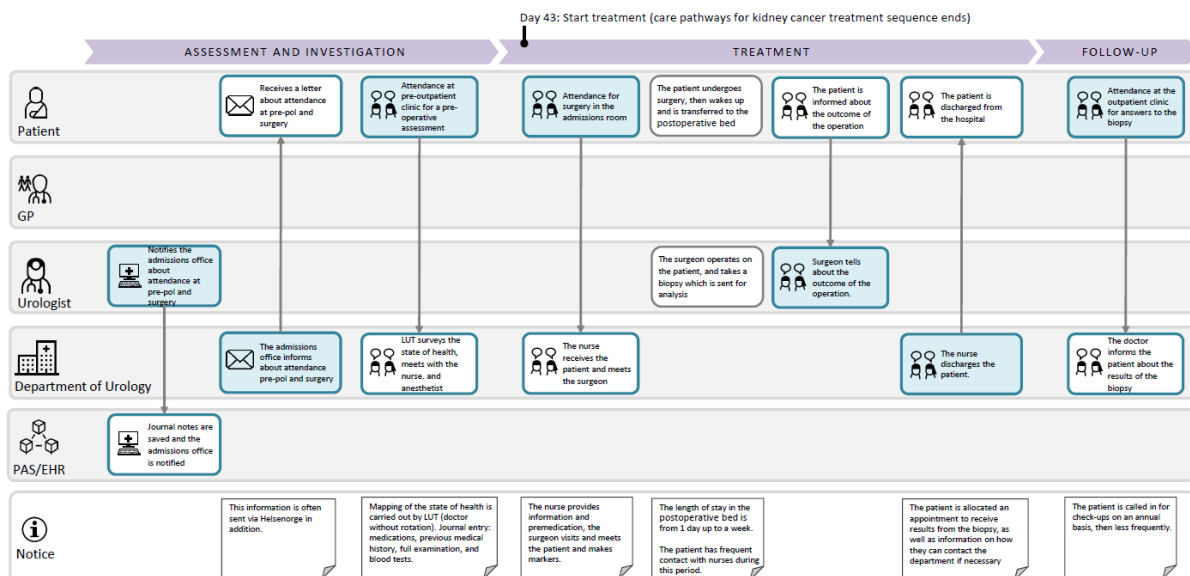


Figure 1: Excerpt from complete kidney cancer patient pathway sourced from Appendix F.

While CJA serves as the methodology employed for the examination of temporal experience, Customer Journey Modelling Language (CJML) constitutes the specific modeling language utilized for this purpose (SINTEF, 2022). The resulting diagram prominently accentuates factors that exert direct influence on the patient's experience within the kidney cancer care pathway, concurrently integrating pertinent contextual elements. Key performance indicators specific to the care pathway for kidney cancer treatment have been integrated to provide a complete evaluation, to wit, treatment course time from the end of the examination to the start of treatment (Helsedirektoratet, 2022). It is imperative to acknowledge that, for the sake of clarity and complexity management, certain simplifications and presumptions have been applied in the graphical representation. These suppositions entail the patient's initial referral to the urology department through a general practitioner (GP), with the GP initiating the process by ordering a computed tomography (CT) scan before proceeding with further referrals. Furthermore, it is worth noting that the diagram does not encompass the potential involvement of case managers, as their role remains unexplored in the research.

The flowchart operates under the presumption that patients partake in preoperative consultations and subsequently undergo surgical procedures. Additionally, the inclusion of a biopsy procedure is contingent upon its concurrent scheduling with the CT scan or its exclusion if it is deemed unnecessary. Notably, the urology ward is portrayed as a multifaceted entity in the diagram, represented by positions including nurses, lower urinary tract specialists, anesthetists, and other relevant personnel actively participating in the care process. These assumptions are strategically embedded in the visualization of the care pathway for kidney cancer patients to streamline its representation while accommodating the responsibilities and interactions within the department, ensuring a focused delineation of the planned pathway.

5.2.1 Actual journey

The patients recruited exhibited variations in the level of details provided regarding their journey, resulting in discrepancies in the frequency of diary updates. These irregularities posed challenges in mapping the extensive network of healthcare actors and touchpoints encountered throughout their individual journeys. The reported touchpoints varied significantly, ranging from 33 to 83, underscoring the wide-ranging nature of their interactions within the system. Ideally, a more consistent level of detail was desired to fully grasp the intricacies of the interactions between healthcare actors. Despite these challenges, the readiness of meticulous data allowed for the creation of a diagram illustrating the patients' actual journeys. This process proved to be moderately straightforward, thanks to the considerable amount of panel data collected. In sum, the analysis focused on the experience of four patients, examining the touchpoints recorded in their diaries over the course of the longitudinal study.

It is noteworthy that none of the actual patient journeys aligned with the planned kidney cancer patient pathway, which consisted of 17 specific action and communication points. This disparity further stresses the dynamic and individualized nature of patient experiences, demonstrating that deviations from the anticipated path are common in real-world settings. Kidney cancer patient #1 provided valuable input into their journey, documenting a total of 49 touchpoints over a three-month period. Additionally, their treating physician from Aker Hospital actively participated in the study by providing additional information through an interview. This combined approach allowed for an inclusive reconstruction of the patient's actual journey using the CJML.

Patient #1's journey summary in the context of tumor detection and subsequent medical interventions involves several stages and transitions. Initially, the tumor is detected incidentally during the discovery of a hernia, leading to the decision to perform a CT scan while residing in the northern part of Norway. The CT results prompt a requisition from the hospital in Finnmark, which is then forwarded to OUS. The patient is subsequently referred from OUS to Aker hospital, where a biopsy is conducted to obtain a definitive diagnosis. Following the biopsy, the patient receives a call from the doctor, informing him about the need for an operation. The operation is performed at Aker hospital,

involving robot-assisted keyhole surgery. Subsequent tests reveal that the patient is cancer-free, indicating a successful outcome. To ensure long-term follow-up and monitoring, the patient is advised to undergo six-monthly examinations, providing ongoing surveillance. This care trajectory demonstrates the multi-faceted nature of the patient's experience, encompassing various medical interventions and evaluations aimed at ensuring their continued well-being.

The recruitment and post-experience interviews with patient #1 shed light on the patient's evolving perception of the communication practices within the system, emphasizing the importance of consistent information provision throughout the entire patient journey. During the initial interview, the patient expresses a general impression of encountering pleasant healthcare staff and a perception of being on a “fast track” within the system. However, the patient highlights a concerning lack of information provided during this early phase. They describe the need to actively seek out information himself, indicating a potential gap in the communication process. Although they receive some information about the upcoming procedures, there is a sense of inadequacy regarding a thorough understanding of what these procedures entail.

Subsequently, in the debrief interview, the patient's overall satisfaction with the communication processes throughout the patient journey became notably evident. The patient acknowledged that during the initial weeks, there existed a slight deficiency in the volume of information provided, necessitating their own proactive efforts to gather necessary details. However, as the patient’s journey progressed, there was a discernible improvement in the communication process, with the patient reporting a perception of receiving ample information. This positive shift in the patient's experience implies that deliberate efforts were undertaken to rectify the initial information deficit, culminating in a more satisfactory experience during the later stages of the patient's trajectory.

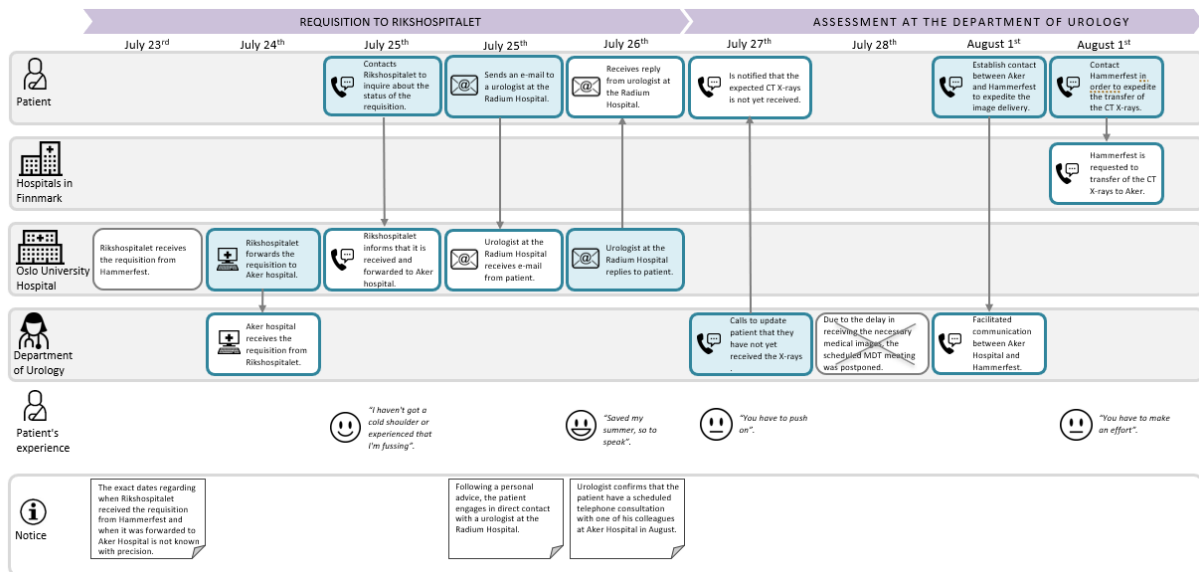


Figure 2: Excerpt from kidney cancer patient #1 real-life journey sourced from Appendix G. The diagram has been processed to enhance anonymization, considering the unique nature of the story.

The actual journey flowchart provides a visual representation of the various stages and interactions that the patient went through during a crucial part of their healthcare encounter. By placing the patient at the center of figure 2, it emphasizes the importance of understanding their experiences, needs, and preferences throughout the entire process. The swimlane diagram allows actors to be au fait with the patient's perspective, enabling them to identify areas for improvement, streamline processes, and enhance the overall quality of care. By considering the patient's point of view, the CJML diagram serves as a valuable tool in patient-centered care and supports efforts to deliver more personalized and effective healthcare services.

5.3 Discussion

Each research question is addressed in the ensuing discussion, facilitating a comparative analysis of the empirical findings with the theoretical underpinnings of the systemic perspective. This section not only underscores the alignment between the observed realities and the systemic principles, but also asserts the equal importance of this discussion vis-à-vis the literature review in elucidating the research inquiries. While the literature review scrutinizes both theories individually, the analysis unfurls a tapestry of diverse perspectives and experiences gleaned directly from the interviewees. Through a judicious juxtaposition of data across respondents, this process uncovers common themes, disparities, and potential avenues for enhancement.

5.3.1 Research question 1

Refocusing on RQ1, *“What are the key principles and concepts of the systemic perspective that can be applied to enhance the management of healthcare delivery?”*, systemic thinking brings attention to aspects that are often missing in the service provision, thereby closing the disparity between actual journeys and patient pathways (Alexander et al., 2018; Brodie et al., 2019; Jaakkola et al., 2015; Vargo & Lusch, 2016, 2017; Vargo et al., 2015). These facets encompass the contemplation of value-in-healthcare-context, the practice of healthcare co-creation, and the delineation of levels of aggregation. Collectively, these key principles promote the delivery of high-quality and efficient care services, ensuring adequate care and respecting patient autonomy. While it's important to note that the concepts derived from the systems logic may not have a direct translation into this context, the following discussion elaborates on how they can be understood and applied within the service provision.

Value-in-healthcare-context

The comprehension and enhancement of patient experiences throughout their journeys are profoundly influenced by their state of well-being (Hollebeek et al., 2019; Vargo & Lusch, 2015). Well-being encompasses various dimensions, including the *“emotional, physical and psychological health or life satisfaction”* (Williams & Radnor, 2022, p. 1130). It underscores the broader objective of promoting holistic health, moving beyond the limited scope of disease management (Ponsignon et al., 2018). By integrating well-being into management, providers can shift their focus from the sole treatment of

medical conditions to encompass the broader impact on the patient's overall well-being. In alignment with SDL principles, it is advisable to refine the concept of well-being to emphasize a more precise understanding. This refined concept, termed value-in-healthcare-context, underscores the importance of considering contextual factors when managing the service provision. It aligns with the central idea that value is co-created through interactions between service providers and patients (Jaakkola et al., 2015; Vargo & Lusch, 2016, 2017). Essentially, this perspective revolves around understanding how healthcare services contribute to the overall value that patients derive from them. Transitioning from a focus on patients' well-being to a focus on value-in-healthcare-context underscores the idea that value emerges when a service proves beneficial and relevant to the beneficiary.

While Lusch and Nambisan (2015) acknowledge the need to move away from a myopic firm-centric focus, their proposition aligns with the GDL notion of considering both value-in-exchange in combination with value-in-use. Nonetheless, these constructs seem somewhat reductionist and lacking in precision, as they insinuate a static and homogeneous valuation of the service provision across all circumstances (Alexander et al., 2018; Lusch & Nambisan, 2015; Lusch & Vargo, 2014; Vargo & Lusch, 2016, 2017; Vargo et al., 2015). Lusch and Nambisan (2015, p. 159) reasons that “*the notion of context is important when discussing value-in-use*”. Value-in-context demonstrates that value is a variable quantity that changes quickly from time to time, from situation to situation, and from actor to actor (Lusch & Vargo, 2014). Bettencourt et al. (2014, p. 50) share the same view of the fourth axiom, stating that “*value is always specific to the context in which a job is done*”. Despite not explicitly putting the value-in-context term in writing, Alexander et al. (2018) stresses the notion of context on all levels of aggregation. Situational circumstances are defined by the beneficiary, and the source of value shows a discrepancy of all beneficiaries (e.g., a treatment plan that offers the possibility of preserving a cancer patient's quality of life may hold significantly more value for them than a more aggressive approach with potential side effects).

Value-in-healthcare-context represents a conceptual evolution rooted in components derived from related concepts, namely, value-in-social-context, value-in-cultural-context and service experience co-creation (Jaakkola et al., 2015; Vargo & Lusch, 2016, 2017). It acknowledges that the value associated with healthcare services is not a static, fixed entity. Instead, it is intricately linked to the specific circumstances shaping the context for the beneficiary. This setting includes several factors (e.g., the patient's specific condition, social and cultural milieu, and the overall quality of their care experience). A patient's perception of value is shaped by how well these dimensions are addressed and integrated into their care. Firstly, the social dimensions within the purview of value-in-healthcare-context encompass the intricate web of interpersonal relationships and interactions that patients engage in within the ecosystem. This entails not only the patient-provider relationship, but also the broader social support networks that patients have access to. The quality and effectiveness of communication and collaboration among patients and healthcare actors significantly influences the perceived value. It

recognizes that the dynamics of support, understanding, and shared decision-making within the social context can significantly impact the patient's journey and their perception of value.

Secondly, cultural dimensions encapsulate the labyrinth web of beliefs, traditions, values, and norms intrinsic to patients, which are cultivated by their diverse cultural backgrounds and affiliations. These cultural constituents wield a profound influence over patients' expectations, attitudes, and proclivities concerning healthcare. An approach characterized by inclusivity and cultural sensitivity recognizes and venerates these cultural elements, seamlessly incorporating them into the care delivery. Such an approach champions patient-centered care that not only acknowledges but also reveres the diversity of cultural perspectives. Thirdly and conclusively, the experiential dimensions scrutinize the quality of a patient's journey. This transcends the realm of clinical efficacy, embracing a holistic assessment of the care experience (e.g., patient's physical comfort, convenience, and emotional well-being during their odyssey). It also encompasses the caliber of interactions between patients and healthcare providers, the physical milieu within facilities, and the overall satisfaction of patients throughout the entirety of the care process. Accordingly, the perception of value-in-healthcare-context is profoundly influenced by the efficacy with which these dimensions are recognized, understood, and seamlessly integrated into the care process. Hence, healthcare management can become more responsive to changing societal patterns, ultimately leading to enhanced public welfare.

Healthcare co-creation

Transitioning from an operand to an operant resource perspective, the framework subtly underscores the inherent expectation of beneficiary engagement in value co-creation activities (Huotari & Hamari, 2017; Nadeem et al., 2021). Central to this framework is the notion that co-creation is fundamentally contingent upon the active involvement of the patient, where their expertise and resources become integral components of the process (Rather et al., 2019). Nevertheless, it is crucial to recognize situations in which patients may assume a more passive role, such as abstaining from engagement in medical dialogues (Nadeem et al., 2021). Active engagement, meaningful communication, and experiential learning do however manifest in a distinctly different manner when compared to traditional product-centric models, where patients often find themselves in passive recipient roles, sometimes inadvertently diminishing value through their resource consumption (Hollebeek et al., 2019; Lusch & Nambisan, 2015; Lusch & Vargo, 2014; Vargo & Lusch, 2017; Vargo et al., 2015).

The theoretical underpinnings of value co-creation are deeply embedded in the concept of “*service-for-service exchange*” (Brodie et al., 2019; Langley et al., 2021; Vargo & Lusch, 2016, 2017; Vargo et al., 2015). Axiom 1 and FP1 of Service-Dominant Logic affirm that “*service is the fundamental basis of exchange*” (Lusch & Vargo, 2014, p. 57). Service, in this context, is defined as “*the application of specialized competences (knowledge and skills) through deeds, processes, and performances for the benefit of another entity or the entity itself*” (Vargo & Lusch, 2004, p. 2). This extends to the realm of self-services, where patients are offered avenues to engage with facilities (e.g., through self-patient

check-in kiosks or traditional in-person registration, all aimed at enhancing the value co-creation process in healthcare).

In acknowledging the heterogeneous character of the healthcare backdrop, it becomes increasingly apparent that a refined comprehension of value co-creation is imperative. This necessitates the adoption of an enhanced conception, termed healthcare co-creation, which penetrates deeper into the foundational principles aligned with a systemic outlook that can be leveraged to optimize the service provision. Within these circumstances, two fundamental principles emerge as exceptionally pivotal, namely self-care and the active engagement of next-of-kin. These principles not only possess the capacity to reshape the experiences of patients but also hold the promise of elevating the standards of management practices to new heights. The foundational works of Lusch and Vargo (2014) serve as a foundational reference for elucidating the concept of self-care within the framework of healthcare co-creation. Self-care, within this framework, takes on a tangible form where patients actively engage in safeguarding their own well-being. This proactive engagement is nurtured and facilitated through collaborative interactions, reflecting a fundamental aspect of co-creation. Patients, in this sense, become more than passive recipients of care (i.e., they evolve into active partners). The recognition of self-care's significance empowers patients to assume an active role in the management of their health, consequently fostering heightened levels of patient satisfaction.

In a similar vein, the wholehearted engagement of next-of-kin can be seamlessly integrated into the paradigm of healthcare co-creation. Next-of-kin refers to individuals affiliated with the patient (e.g., family members or close friends), who ardently advocate for the patient's well-being throughout their journey. These individuals often serve as invaluable founts of information and emotional sustenance, equipped with firsthand knowledge of the patient's condition, treatment history, and responses to medical interventions. The participation of caregivers empowers patients, endowing them with a sense of ownership and agency. When next-of-kin are actively involved in care planning, patients are more likely to experience a sense of being heard, respected, and included in their own care. Next-of-kin ought to be acknowledged as entities with a discernible impact on the value generated within the service environment, given that their engagement extends beyond a peripheral role. Recognizing the influence wielded by next-of-kin underscores their importance in healthcare co-creation. Nevertheless, the effective integration of next-of-kin in service provision encounters challenges (e.g., communication obstacles, concerns related to confidentiality, and cultural or social dynamics) that might affect the willingness or capacity of caregivers to participate. The establishment of clear guidelines and protocols for next-of-kin involvement becomes imperative, ensuring the preservation of privacy rights and ethical considerations, while maximizing the advantages of their contributions to healthcare co-creation.

Hierarchical aggregation levels

Systemic thinking surpasses the traditional patient-provider dyad and embraces a holistic comprehension of service provision that extends across hierarchical levels. To fathom the intrinsic dynamics of healthcare co-creation within the ecosystem, a three-tiered structure proves indispensable. This refers to the idea that the macro level system (i.e., the healthcare system in its entirety) exerts its influence upon meso and micro systems, ultimately shaping the behaviors and actions of the actors within those systems (Alexander et al., 2018; Brodie et al., 2019; Langley et al., 2021; Lusch & Vargo, 2014; Vargo & Lusch, 2016, 2017; Vargo et al., 2015). Hollebeek et al. (2019) highlight the significance of adopting the theoretical underpinnings as delineated by Coleman (1986, 1994) to clarify actors' engagement from macro and micro dimensions. A duplex level viewpoint recognizes the existence of varying degrees of influence that shape management practices.

An additional stratum can be discerned at the meta level, as to where multiple healthcare industries coexist (Alexander et al., 2018). Hither, healthcare co-creation may involve collaboration and resource-sharing between sectors to tackle complex challenges or promote innovations in patient care. Transitioning to a macroscopic perspective unveils an array of overarching systemic factors, including organizational structures that exert significant influence over the comprehensive design and operation of service delivery (Vargo & Lusch, 2016, 2017). These macro level factors have a direct impact on the meso level systems (e.g., hospitals, clinics, primary care practices). The institutions formulated at the highest echelons provide the framework within which these organizations operate, dictating how the service provision is structured and coordinated within their respective domains.

At the micro level, individual healthcare professionals, patients, and their families are subject to the influence of group level arrangements (Vargo & Lusch, 2016, 2017). The organizational cultures, values, and practices of facilities within which they work or seek care impact their behaviors, attitudes, and decision-making processes. To illustrate this, consider a macro level policy emphasizing patient-centered care coordination gradually percolates down to the meso level, for instance influencing how organizations develop their management strategies and implement protocols. Subsequently, this affects the behaviors and practices of personnel at the microscopic level, shaping how they interact with patients and coordinate care across different stages of the service provision.

Medical coordinators assume a broader, macroscopic perspective when piloting the complexities of healthcare systems. They possess an overarching view of the system as a whole, thereby necessitating a shift in their approach. Specifically, it is imperative for them to transition from a focus on healthcare co-creation or the general "*viability of a relevant system*" to a more refined mindset that centers on the value-in-healthcare-context for each patient (Lusch & Vargo, 2014, p. 56). In contrast, clinicians, who engage in direct patient care and maintain a micro level perspective, also require a perspective adjustment. They must recognize that the overall viability and success of the ecosystem are intricately

linked to the value generated at the individual level. This signifies the essential idea that value creation operates at multiple levels of aggregation. While value creation at macro level might seemingly indicate an efficiently functioning healthcare system, a closer examination of individual patient journeys may reveal disparities that challenge this apparent efficiency. This underscores the significance of harmonizing these macro and micro perspectives to ensure the overall efficacy and success of the system. It emphasizes that the system's overall performance hinges on the individual experiences and the value that each patient receives, underscoring the need for a balanced and integrated approach to healthcare management.

A salient aspect of patient pathways, as accentuated by Lusch and Vargo (2014), is the temporal dimension inherent in a service ecosystem. Actors and auxiliary services, are not static entities but are spread across both space and time. The spatial dimension can be geographic, with actors occupying physical locations (Lusch & Vargo, 2014). It can also be relational, where actors are interconnected through networks, relationships, and collaborations that collectively form the structure of the ecosystem. Patient pathways serve as a pertinent example of this spatial-relational interplay, as patients traverse various physical locations, all while engaging with a diverse array of providers and services. The process of healthcare co-creation unfolds across distinct phases, with a paramount emphasis on the temporal dimension, a foundational consideration for comprehending the evolution of this phenomenon throughout a patient's odyssey (Lusch & Vargo, 2014). As to where efforts may focus on preventive measures, co-creation commences even before a patient receives a formal diagnosis (e.g., vaccinations, screenings, lifestyle interventions, and health education).

The temporal network structure places emphasis on the imperative of data continuity, highlighting the indispensable role of maintaining longitudinal records that span a patient's entire lifetime (Lusch & Vargo, 2014). These records are invaluable as they provide personnel with a holistic view of a patient's history, enabling them to make informed decisions and deliver continuous, personalized care.

Conversely, the macro level shifts the focus towards population health, adopting a broader societal ratio, for instance, addressing health disparities, and the overall well-being of communities and populations (Lusch & Vargo, 2014). This elevated vantage point extends beyond individual patients to encompass entire communities. Strategic planning and policymaking are paramount at the macro level. Executives, administrators, and governmental bodies define the overarching framework within which healthcare organizations operate and define the broader goals and objectives of the service provision.

The healthcare ecosystem fundamentally functions as a tightly interwoven system, where both bottom-up grassroots initiatives and top-down regulatory measures exert a continual reciprocal influence (Lusch & Vargo, 2014). This intricate interrelationship underscores the significance of recognizing the dual nature of causality. On one hand, the process upward initiatives represent grassroots efforts and micro level actions by actors, which contribute to the collective healthcare experience. Conversely, the phenomenon of top-down causality elucidates the profound influence wielded by healthcare

regulations and policies originating from the highest echelons of governance. These institutions exert a far-reaching influence on the quality of care and the overall patient experience, underscoring the magnitude of macro-level decisions in shaping the realities of the service provision.

A comparative examination of the temporal and macro dimensions reveals an interconnection, characterized by their intrinsic complementarity rather than conflict. The temporal level places primary emphasis on individualized, patient-centric care, emphasizing the management across phases of the patient's journey over time. In contrast, the macro level furnishes the overarching systemic framework within which this personalized care is dispensed. These levels are fundamentally interleaved, and their convergence substantially contributes to the progression of healthcare delivery. Recognition of this synergistic interplay empowers executives to aspire to a nuanced equilibrium between patient-centered, time-sensitive care and the establishment of a well-structured, enduring ecosystem. This alignment seamlessly aligns with the overarching research question's objective, which seeks to enhance the management of the service provision while acknowledging the intricate dynamics inherent within the healthcare system.

5.3.2 Research question 2

In addressing RQ2, which probes how the systemic perspective influences communication strategies and practices along the continuum of care, we uncover insights into the transformative potential that this perspective imparts to healthcare communication. This perspective accentuates the significance of a shared institutionalized language, recognizing institutionalized responsibilities, and promoting actor-to-actor interactions. This perspective, under the sway of communication and language dynamics, has *“led to the rise of cocreation practices and systems”* (Lusch & Vargo, 2014, p.138). Integrating the systemic perspective into the service provision involves acknowledging that communication is not unidirectional but a collaborative process with multiple participants. It underscores that communication isn't merely operational but a means for value-in-healthcare-context and healthcare co-creation. Let's explore further the role of the systemic perspective, grounded in SDL, in shaping communication strategies and practices across the continuum of care.

Language as a shared institution

As articulated by Lusch & Vargo (2014, p. 4) the systemic perspective underscores the presence of *“systemic interdependencies”* permeating society. These interdependencies give rise to institutional construct, which are essentially mechanisms designed to foster efficient exchange systems. These institutions encompass a wide spectrum, namely, *“language, norms, industries, markets, and organizations”* (Lusch & Vargo, 2014, p. 4). Their overarching purpose is to facilitate the exchange of value for the sake of coordination. Effective care hinges significantly on communication, imbuing this systemic perspective with profound impact. Among the key institutions emphasized by Lusch and Vargo (2014), language assumes paramount importance in healthcare communication. Language transcends being a mere tool for transmitting information, to be exact, it acts as a conduit for fostering shared understanding, collaboration, and healthcare co-creation.

Healthcare communication operates within a complex network of interdependencies, akin to the broader societal systems delineated by Lusch and Vargo (2014). Effective communication extends beyond the confines of the patient-provider dyad, encompassing a complex web of interactions. In this ecosystem, both linguistic elements and established communication norms occupy critical positions, orchestrating the seamless dissemination of information and fostering a collective comprehension among participants concerning healthcare processes and objectives. These norms and practices entrenched within healthcare organizations are paramount within the systemic perspective. They not only guide communication strategies and practices but also exert a substantial influence on how information is shared, decisions are reached, and collaborative endeavors are structured. Healthcare professionals operate within a framework of norms, both clinical and ethical (e.g., informed consent necessitates clear communication about the risks and benefits of treatment). Adherence to these norms ensures that communication practices align with accepted standards and expectations.

Understanding the interdependencies between language, norms, and healthcare organizations is pivotal for designing effective communication strategies that optimize the service provision (Lusch & Vargo, 2014). Essentially, organizations themselves serve as institutions that shape the communication terrain within the continuum of care. These entities lay down communication protocols and standards, thereby exerting their influence on how information is documented, disseminated, and made accessible. These institutional bodies possess the capability to mold the communication culture within their respective environments, a factor that can shape the overall patient experience. Expanding on the insights provided by Lusch and Vargo (2014, p.138), it becomes evident that "*language helped standardize the relational statements used in communication*". Language serves as a shared institution that not only standardizes but also influences the interactions among healthcare actors. It provides a unified framework for conveying complex medical information, thereby promoting efficiency and effectiveness in communication. Notably, the scope of language extends beyond verbal discourse and encompasses a myriad of forms, including written and visual elements, as well as "*symbol systems to enable interaction and exchange, with and among others*" (Lusch & Vargo, 2014, p. 120). These elements embody the capacity to express empathy, instill trust, and encourage active engagement. Collectively, they constitute an ecological communication unit that significantly influences the exchange of information and the cultivation of relationships among various actors. Thus, effective communication hinges on the establishment of a shared language, one that transcends linguistic barriers to ensure that every participant comprehends and contributes to the co-creation of value within the system.

Effective communication is a delicate balancing act, particularly given the diverse backgrounds and varying levels of health literacy, making a shared language a critical element that facilitates a common understanding, for instance, using hematuria instead of blood in the urine, or ECOG instead of performance status might result in confusion (Hardavella et al., 2017). Patients require the ability to

decipher medical jargon, while healthcare providers must convey intricate medical information in a manner that is accessible and logical to patients. Shared language only functions as a unifying agent but also facilitates a standardized interpretation of medical terminology (e.g., healthcare professionals use standardized terms and codes to describe conditions, procedures, and medications). This standardization ensures the precision of information transfer, thus mitigating the susceptibility to misinterpretation or misapprehension. The cultivation of lucid and standardized communication to foster a shared understanding among all actors signifies a fundamental stride in the process of co-creating value along the continuum of care.

A cornerstone of standardized communication in healthcare pertains to the development and implementation of care pathways, which assumes particular significance in the context of cancer treatment. These care pathways are meticulously crafted, evidence-based guidelines that delineate the recommended steps and actions for managing specific medical conditions (e.g., kidney cancer). Essentially, they function as blueprints within interdisciplinary teams, offering a structured and standardized approach to communication. They establish a shared lexicon for the deliberation of treatment strategies and the continuous monitoring of patient progress. Through interdisciplinary communication, professionals can collaboratively assess the patient's condition, engage in thorough discussions about various treatment options, and collectively arrive at well-informed decisions regarding the most appropriate course of action. The efficacy of care pathways resides in their capacity to delineate the most efficacious treatments and interventions tailored to specific medical conditions. This precision substantially mitigates the potential for divergences in communication and care approaches that may arise when disparate healthcare providers confront the same condition with varying strategies. By offering a lucid blueprint for care, these pathways ensure the congruity of healthcare teams, thus minimizing the peril of miscommunication and misconceptions. This illustrates the importance of communication strategies in configuring the service provision to the advantage of actors. Ultimately, care pathways for cancer treatment serve as an illustrative instance of how standardized communication practices contribute to healthcare co-creation across the continuum of care.

Institutionalized responsibilities

Incorporating caregiving responsibilities and handovers into the service provision are instrumental in emphasizing the engagement of diverse healthcare professionals, shedding light on the imperative need for efficient communication practices across the continuum of care. Caregiving responsibilities encompass the tasks and duties assigned to actors involved in a patient's care and the exchange of crucial information (i.e., activities, diagnosis, treatment, monitoring, and ongoing support). It is paramount to accurately delineate these responsibilities to ensure the flow of medical information and patient-provider communication. By explicitly defining and effectively communicating caregiving responsibilities, healthcare providers can significantly mitigate the risk of fragmented message

conveyance. This, in turn, guarantees that all participants involved comprehend their roles and obligations, ultimately contributing to the optimization of the healthcare ecosystem. Handovers, on the other hand, entail the transfer of accountability for a patient's care from one individual or team to another. Despite the ostensibly straightforward representation of this concept, often depicted as a mere arrow connecting flowchart boxes within patient pathways, its actual execution frequently introduces multifaceted challenges in practice (e.g., confusion, fragmentation, and misunderstandings). Effective handovers require precise communication to ensure the continuity of care. In cases where clear communication and coordination are lacking during handovers, it can result in compromised continuity.

When one contemplates the import of caregiving responsibilities and the labyrinth processes entailed in handovers, it becomes evident that institutionalized responsibilities provide a framework that is not only more comprehensive but also inherently adaptable. This adds a layer of complexity to managing healthcare communication. Their impact is underscored by axiom 2 and FP6 that postulates "*value is co-created by multiple actors, always including the beneficiary*" (Hollebeek et al., 2019; Vargo & Lusch, 2016, p. 8). Here, the beneficiary pertains to the recipient of the service benefit, namely the patient, underscoring that value is not engendered in isolation but rather through the collaborative efforts of a multitude of actors. In the context of accountabilities and handovers, it becomes evident that both primary actors and ancillary figures (e.g., laboratory technicians and regulatory bodies) play integral roles in healthcare co-creation. The acknowledgment of a constellation of contributors to the service provision accentuates the need for clear role delineation. Effective communication among these myriad actors is pivotal to ensure the fulfillment of both the patient's needs and the overarching objectives of the service provision.

The delineation of boundaries within an ever-expanding ecological unit begets salient questions critical to the enhancement of communication strategies and practices. For instance, it prompts an inquiry as to whether laboratory technicians should be encompassed within this unit and entrusted with the responsibilities of communication. The determination of these demarcations resides within the purview of the overseeing analyst and is conventionally denoted as the preferred unit of analysis or level of analysis (Alexander et al., 2018; Brodie et al., 2019; Font et al., 2021; Kumar et al., 2019; Langley et al., 2021; Vargo & Lusch, 2017). This perception underscores the necessity of distinguishing between the scope of analysis and the "*institutionalized roles and responsibilities of each social and economic actor*" within the ecosystem (Lusch & Vargo, 2014, p. 190). As emphasized by Lusch and Vargo (2014), an indefinite or vague delineation of these roles can lead to suboptimal value co-creation. Thus, it is crucial to comprehend that adopting a broad perspective does not inherently imply that laboratory technicians, for instance, bear the direct responsibility of conveying messages to patients. Instead, it underscores the collective onus upon all actors within the ecosystem to assume their respective roles and responsibilities. However, it is imperative to acknowledge that

institutionalized responsibilities in healthcare are not immutable entities, nor are they universally homogenous across all care systems. Their character and efficacy can exhibit significant variations contingent on the specific nuances of diverse ecosystems, the cultural contexts in which they operate, and the distinct expectations of professional communities involved.

Actor-to-actor interactions

In conventional healthcare settings, communication predominantly occurs within isolated silos, where different service providers function independently and may lack an inclusive view of a patient's overall care plan. This fragmented communication pattern can lead to issues (e.g., misunderstandings, errors, and inefficiencies) in the delivery of care. However, the promotion of interactions among actors, fostering interdisciplinary communication, seeks to break down these silos, ultimately facilitating seamless care coordination. Effective communication transcends the boundaries of distinct disciplines (e.g., pharmacology, or cardiology). It accentuates the necessity of interdisciplinary communication to ensure the smooth flow of information and the engagement of relevant actors at different stages of the service provision. This entails establishing robust communication channels between primary care providers (e.g., nurses or general practitioners), specialist medical practitioners (e.g., oncologists or urologists), and other members of the team. Interdisciplinary communication cultivates a holistic understanding of the patient's needs, facilitates collaborative care planning, and enables the efficient coordination of services.

Actor-to-actor interactions in the provision of healthcare services, particularly through the concepts of co-choice and informed consent, is promoted by “*actor-to-actor interactions [that] help to create the environment that is the playing field for their future actions*” (Lusch & Vargo, 2014, p. 24). These interactions at the micro-level between actors are paramount components in the grand architecture of communication. They are not isolated or discrete events, rather they serve as the foundational elements upon which future collaborative endeavors in care delivery, informed decision-making, and healthcare co-creation. The significance of these interactions cannot be overstated. They are instrumental in shaping the quality and effectiveness of the service provision, patient experiences, and overall healthcare delivery. Effective actor-to-actor interactions create an environment where interdisciplinary communication thrives, thus optimizing service provision. It is through these interactions that actors come together to co-create value and make well-informed choices within the ecosystem.

The nexus between informed consent and co-choice seamlessly intertwines with actor-to-actor interactions, where individual values, preferences, and unique life experiences hold profound sway over the decision-making process. The acquisition of informed consent from patients transcends being a mere legal and ethical requisite, which serves as a cornerstone of ample service provision.

Unfortunately, this critical element is frequently either overlooked or inadequately addressed within patient pathways. The significance of informed consent manifests in its capacity to empower patients with the vital information necessary to make autonomous decisions regarding their well-being. The

incorporation of the informed consent process serves a dual purpose. Firstly, it reinforces patient autonomy, aligning seamlessly with the systemic perspective's fundamental tenets of value co-creation. Secondly, it ensures strict adherence to established legal standards, a focal component of the systemic perspective's influence on healthcare practices.

Informed consent is inextricably intertwined with the concept of co-choice, an approach that entails active patient involvement in the selection of healthcare services, treatment options, and care plans. Co-choice operates under the premise that each patient possesses unique preferences, values, and objectives that must be given due consideration in the process of decision-making. Essentially, co-choice embodies the principles of actor-to-actor interactions, with the patient positioned at the core of the healthcare co-creation process. It acknowledges the patient's role as a co-creator of value within the ecosystem, aligns seamlessly with the tenets of the systemic perspective (Vargo & Lusch, 2016). This collaborative approach, which emphasizes patient-centered care and upholds ethical standards, assumes great significance in the provision of healthcare services that are contextually relevant. It exemplifies the influence of the systemic perspective on the transformation of communication strategies and practices, ultimately fostering a healthcare continuum that is more patient-centric, efficient, and firmly grounded in ethical principles.

Social systems are considered “*both the medium and the outcome*”, but is continuously experimental in its nature given that the beneficiary is an equal actor in value co-creation (Font et al., 2021; Hollebeek et al., 2019; Jaakkola et al., 2015; Kumar et al., 2019; Lusch & Nambisan, 2015; Lusch & Vargo, 2014, p. 24; Vargo & Lusch, 2017; Wu et al., 2014). These systems maintain an inherently experimental nature, largely due to the importance of the beneficiary as an equal actor in value co-creation. Within this framework, an emphasis is placed on fostering a profound sense of connection and social interaction, highlighting the intrinsic relationship-oriented and interactive aspects that underlie the emergence of value. In this context, informed consent surpasses the mere provision of information to patients, evolving into a dynamic and collaborative dialogue between healthcare providers and patients. Both parties actively contribute their expertise, insights, and perspectives, culminating in a shared decision-making process. This approach aligns with the overarching research question, shedding light on how the systemic perspective influences communication strategies and practices along the continuum of care. It accentuates the significance of social systems, value co-creation, and informed consent as integral components of a patient-centered and interaction-driven healthcare ecosystem.

6.0 Conclusion

In conclusion, returning to the problem statement of "*How can an expanded viewpoint foster the delivery of healthcare services that are both of high quality and efficiency?*", unveils the apex of a conceptual framework. Drawing upon Coleman's (1986, 1994) seminal works, it can be metaphorically likened to a vessel navigating the healthcare landscape. It constitutes a construct emblematic of the perpetual, dynamic, and interactive process of value co-creation within the domain, as depicted in figure 3. Aptly christened as the Healthcare Value Dynamics Framework, it encapsulates the intricate interplay of foundational elements, interrelationships, and catalysts for action. It accentuates the symbiotic relationships among actors, and their respective contributions to the formulation of value derived from the service provision. In its ultimate capacity, it emerges as a compass for healthcare management and communication, adeptly steering the trajectory of service provision, enhancing the quality of patient experiences, and facilitating the promotion of effective healthcare co-creation.

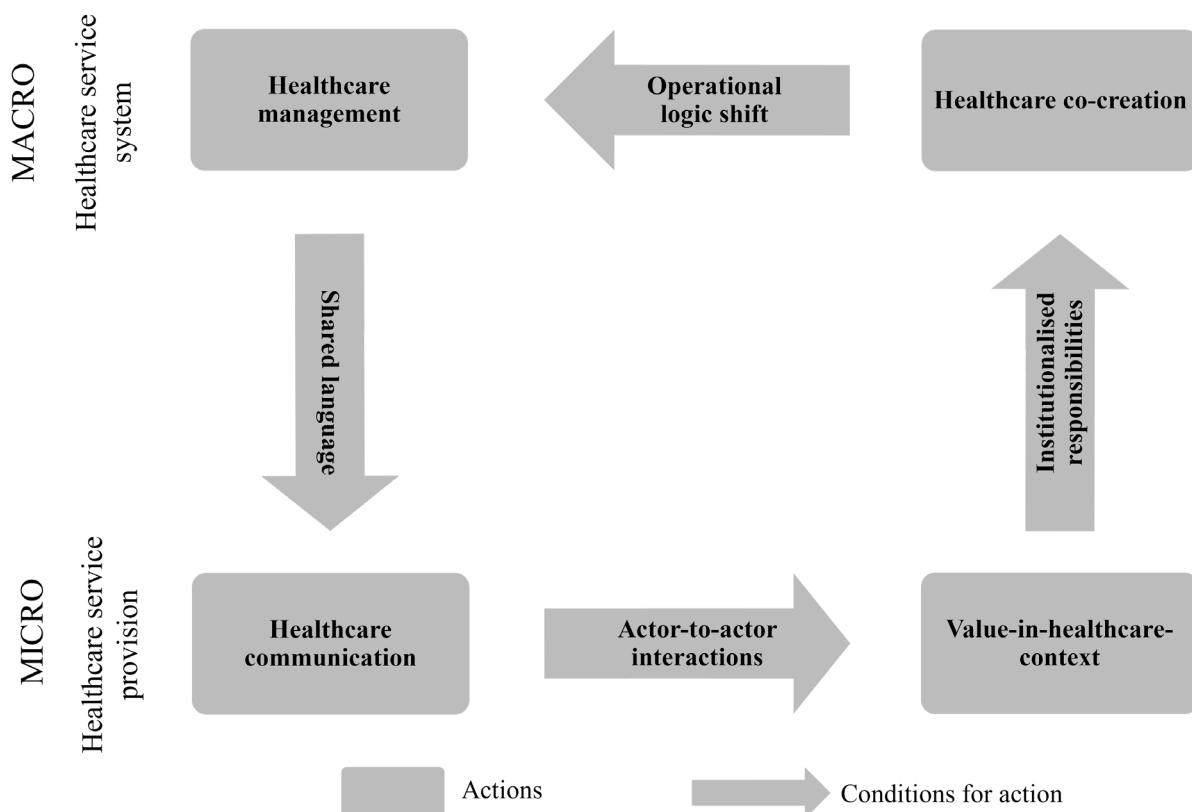


Figure 3: Healthcare Value Dynamics Framework.

Within the epitome of this framework, the conditions for action serve as the indispensable prerequisites for fostering substantive interactions and cooperative initiatives among the various actors. More precisely, these conditions encompass four key components, namely shared language, actor-to-actor interactions, institutionalized responsibilities, and the operational logic shift, as

expounded within the framework. Conversely, the term actions denote the outcomes resulting from the framework's implementation, encompassing the overarching objectives that the ecosystem aspires to attain. In the context of the Healthcare Value Dynamics Framework, these actions manifest as the ultimate goals of advancing management for the greater public health good, enhancing effective communication, nurturing value-in-healthcare-context, and promoting the co-creation of value. The segments positioned on the left side, designated as management and communication, are intricately interconnected with the aspect of service provision. They serve as the conduits through which fundamental concepts emanating from SDL are operationalized, notably, the notion of a shared language. Concurrently, the framework adheres closely to systemic principles, offering a comprehensive perspective on the labyrinth healthcare system. These principles exert significant influence, contributing to the intricate interrelationships woven throughout the ecosystem, with a particular emphasis on the experiential dimension of the patient and the active process of value co-creation along their trajectory.

At the zenith of the framework, the macro label signifies the overarching system that exerts a substantial impact on healthcare management and communication. Notwithstanding, the lower section represents the micro level, which pertains to the service provision at the individual patient level, where practices and decisions have direct consequences for patients. The concentric layers of aggregation serve as a bridge connecting the micro level (i.e., healthcare service provision), and macro level (i.e., healthcare service system), with institutions occupying a central position in this interplay. Of noteworthy importance is that value-in-healthcare-context predominantly manifests at the micro level, while healthcare co-creation operates at a higher macro level. Throughout the analytical examination, a pronounced emphasis is placed on the dynamic interactions between these micro and macro levels, thereby recognizing the bidirectional influence characterizing their relationship.

The segment dedicated to healthcare management for the advancement of public health is intrinsically linked with the exploration of the first research question, centering predominantly on the administrative aspects of the ecosystem. These institutional components wield a substantial influence over the practices of communication at the macro level of the ecosystem. Accordingly, shared language pertains to a commonly agreed communicative foundation, or a standardized lexicon collectively employed within institutional frameworks or the broader healthcare system.

Communication, a pivotal element closely tied to the second research question, primarily delves into the exchange of information and interaction among actors. However, the concept of actor-to-actor interactions goes far beyond conventional communication. It sheds light on the ability of actors to engage effectively with one another, encompassing essential practices (e.g., co-choice and informed consent). Co-choice is a process where patients play an active role in choosing their treatment options from a range of possibilities. This involves them in the decision-making, empowering them to select the treatment options that align with their preferences. The outcome of this is the realization of *value-*

in-healthcare-context, meaning the product of co-choice and beneficiary involvement in shaping their journey.

Stemming from the synthesis of empirical insights and theoretical contemplation in the preceding chapter, a precise elucidation of value-in-healthcare-context emerges. It can be defined as the intrinsic worth that manifests within the healthcare context, predominantly attributed to the dynamic and intricate relationships that unfold among diverse actors. This conceptualization systematically factors in contingency variables and recognizes the distinctive interplays that occur amongst these actors within the ecosystem. The concept of value-in-healthcare-context pivots on the notion that every individual patient perceives the creation of value within the system. Consequently, it affords a multi-dimensional grasp of value, transcending the confines of traditional economic metrics. It encompasses not only the clinical dimensions but also the broader facets of healthcare. This perceptual insight, in turn, serves as a catalyst for the phenomenon of healthcare co-creation, framed through the perspective of institutionalized responsibilities. It accentuates the significance of caregiving responsibilities and the subsequent transfer of responsibilities. These aspects are pivotal considerations when contemplating the transference of value from the micro-level, represented by the individual patient's experience, to the macro-level, encompassing the broader system.

Furthermore, the conceptualization of healthcare co-creation has emerged as an apt and salient construct. In a succinct and precise definition, healthcare co-creation delineates a dynamic process wherein the generation of value unfolds collaboratively among a consortium of actors. These actors encompass a spectrum, ranging from patients and healthcare providers to facilities and the indispensable support services embedded within the labyrinth tapestry of the service provision. This complex process entails the active engagement and contribution of these actors, as they collectively harness specified resources and engage in interactions within the multifaceted milieu, thereby delineating and configuring the overarching value emanating from the ambit of services. This transition toward the notion of healthcare co-creation epitomizes an advanced perspective regarding the multifarious facets intrinsic to the domain of management and the mosaic of patient experiences. It underscores the proactive roles played by patients and their proximate familial connections in the definitive shaping of the value derived from healthcare services.

At an abstract level of analysis, the impact of healthcare co-creation on healthcare management gives rise to a transformation of the foundational principles and operational methodologies that serve as the underpinnings of healthcare systems. The operational logic shift signifies a restructuring of the core paradigms, methodologies, and philosophical underpinnings that form the very bedrock of healthcare management. It is paramount to underscore that this shift does not represent a departure from the significant strides made by the public sector in recent times towards embracing agility and relational dynamics. Rather, it embodies a nuanced acknowledgment of the inherent tensions that emerge when

embracing a disciplined and systemic approach. This acknowledgment is exemplified by the imperative of preserving specialization among personnel while concurrently empowering patients. The operational logic shift underscores the necessity of achieving a harmonious balance between control functions and patient empowerment, hierarchical leadership and lateral relationships, as well as standardization and the fostering of organizational learning concomitant with the pursuit of continuous improvement. It constitutes a dynamic and ongoing paradigmatic transition, endowing healthcare management with the adaptability required to continually respond to the evolving demands of patients and the shifting dynamics of the broader ecosystem. As a result of this transformation, the sector is poised to elevate the quality of care, enrich the overall patient experience, and make a substantial and enduring contribution to the overarching objective of advancing public health outcomes.

6.1 Practical implications

The framework presented herein bears practical relevance in the healthcare domain, not only by offering an innovative perspective to grasp the fundamental principles that underlie ecosystems but also by furnishing a practical avenue to implement these principles in concrete scenarios. It is essential to underscore that a significant practical dimension of the Healthcare Value Dynamics Framework lies in its capacity to disentangle the dichotomy between principles and practices, as expounded in table 1. SDL principles are conceptual and theoretical, serving as foundational constructs for the comprehension of value co-creation and service delivery. In contrast, patient pathway practices are pragmatic and operational, focusing on the tangible execution of processes in the real world. This demarcation serves to facilitate healthcare professionals, administrators, and policymakers in recognizing that while systemic principles elucidate the overarching strategy for healthcare co-creation, it is the practical implementation that has a direct impact on patient experiences and the service provision. The framework's genuine transformative potential becomes apparent when these two dimensions are harmoniously synchronized.

Table 2: Distinguishment between principles and practices.

Aspect	SDL Principles	Patient Pathways Practices
Nature	Conceptual and theoretical, serving as the foundational basis for comprehending the intricacies of the creation of value.	Pragmatic and operational, centering on the tangible, real-world processes and interactions that transpire between patients and healthcare providers.
Macro vs. micro	Emphasizes high-level systemic concepts and principles, shaping the overarching perspective of the service provision.	Concentrates on day-to-day operational practices within the healthcare system, involving interactions between healthcare actors.
Value co-creation	Highlights the context-dependent and patient-centered aspects of healthcare co-creation, concentrating on the underlying principles.	Concerned with the practical aspects of how patients actively engage in value-in-healthcare-context.

Contribution to framework	Shapes the foundational principles that underlie healthcare co-creation and systemic dynamics.	Ensures efficient healthcare service delivery and active patient involvement in care processes.
Key components	Value-in-healthcare-context, healthcare co-creation, operational logic shift, institutionalized responsibilities, actor-to-actor interaction, shared language, and levels of aggregation.	Informed consent, handovers, public health, well-being, self-care and the active involvement of next-of-kin.
Implications	Contributes to the academic domain by establishing a theoretical basis for healthcare co-creation.	Provides practical insights and guidance to healthcare practitioners, enhancing the application of healthcare management.
Scenario	Guide the design of institutional systems that facilitate value co-creation within healthcare.	Find practical manifestation in the daily processes where providers ensure a seamless transition and continuity of care for the patient, improving their journey.

6.2 Theoretical implications

The abstract nature of Service-Dominant Logic has historically evoked reluctance among early academics to categorize it as an inclusive theory within the marketing discipline (Lusch & Vargo, 2014). Instead, Lusch and Vargo (2014, pp. 134, 211) characterized SDL as a perspective or lens, a categorization that was cautiously framed, suggesting its potential to “*perhaps serve as a foundation for a general theory*». Notably, SDL has spawned the development of derivative constructs that represent the unfolding richness of its theoretical dimensions (e.g., Customer-Dominant Logic and Service Logic). In a prospective outlook articulated by Vargo and Lusch in 2017, the trajectory of systemic logic was envisioned along three potential paths, specifically, a general theory, midrange theory, or serve as foundational framework. The pathway it eventually follows remains open, allowing for a range of theoretical applications and implications to be explored. This strategic flexibility ensures the continued dynamism of SDL, making it both a fertile ground for the development of marketing management theory and a malleable lens for understanding the complexities of value creation within service ecosystems (Vargo & Lusch, 2017). Inarguably, SDL has transcended its initial confines and seeded the expansion of various conceptual domains, such as customer engagement and actor engagement in networks, complexity theory and service ecosystem perspective, revealing its capacity to stimulate the formulation of novel theoretical frameworks (Brodie et al., 2019; Kumar et al., 2019; Vargo & Lusch, 2017; Vargo et al., 2015; Wu et al., 2014).

Recent scholarly investigations have elucidated a noteworthy metamorphosis in the standing of SDL, which has evolved into a metatheoretical framework characterized by a comprehensive categorization of the lens based on the development of mid-range theories (Lusch & Nambisan, 2015; Lusch & Vargo, 2014; Vargo & Lusch, 2018). Although Vargo and Lusch (2004) initially introduced SDL as a novel perspective, it is gradually gravitating towards the realm of a general theory within the

marketing discipline. It is imperative to acknowledge that, as of the present state of empirical investigation, SDL has not ascended to the echelon of a fully-fledged scientific theory endowed with a robust practical applicability. Hence, this research undertook a rigorous examination of SDL's malleability and tenacity, stretching its boundaries into a specialized healthcare ecosystem. The transplantation of SDL into the multifarious and stringently regulated milieu of patient pathways subjected it to rigorous scrutiny and evaluation.

This endeavor holds academic significance by advancing the trajectory of Service-Dominant Logic to new heights, culminating in the establishment of an ample framework firmly rooted in systemic principles. Extending beyond its immediate healthcare context, the theoretical implications of this study are manifested in the Healthcare Value Dynamics Framework, coupled with its proposed conceptualizations of value-in-healthcare-context, healthcare co-creation, and the subsequent operational logic shift. It is crucial to underscore that the definitions presented, although original, are not intended to be universally definitive or unalterable. Rather, they serve as a foundational underpinning for the continual exploration of value co-creation against the healthcare backdrop.

Subsequent research endeavors should be oriented toward the refinement and expansion of the presented definitions, thus underscoring the imperative necessity for an ongoing, dynamic process of exploration, enhancement, and synthesis of the fundamental principles that constitute the bedrock of SDL. This concerted effort not only serves to fortify the Healthcare Value Dynamics Framework's adaptability and relevance within a complex sector but also contributes substantively to the continuous evolution of SDL, guiding it towards attaining the status of a general theory. The theoretical dynamism embedded in this research positions SDL as a keystone in contemporary marketing management thought, and in so doing, leaves its ultimate theoretical identity as an open frontier ripe for perpetual exploration and development. By actively addressing the extant gaps and discerning prospective areas for advancement within SDL, this study assumes a part in propelling the broader discourse that revolves around the foundational tenets of Service-Dominant Logic. Through this scholarly endeavor, it not only pushes existing research horizons but also unfurls new avenues for pioneering research and innovative scholarship.

7.0 Limitations and avenues for future research

The acknowledgment of specific limitations and the careful delineation of avenues for future research stand as imperative endeavors within the scholarly landscape (Clark et al., 2021). In consonance with the principles of methodological transparency and rigor, this section employs the Standards for Reporting Qualitative Research (SRQR) framework to dissect and examine these aspects comprehensively, spanning across pivotal sections encompassing the introduction (S1-S3), method (S4-S11), results (S12-S14), and discussion (S15-S19) (O'Brien et al., 2014). The SRQR guidelines, designed to augment the quality of reporting in qualitative research studies emphasize crucial facets (e.g., transparency, credibility, and methodological rigor). The adaptation of the SRQR framework to illuminate and scrutinize the limitations inherent within this research serves the purpose of enhancing the precision and depth with which these constraints are explored.

7.1 Introduction: narrow scope and theoretical emphasis

An inherent limitation within the introductory phase of this study (S1-S3 in SRQR) is the constraint imposed by its narrow scope, coupled with its predominantly theoretical orientation (O'Brien et al., 2014). The study's exclusive examination of kidney cancer patient pathways, while contributing to theoretical depth, constricts the extent to which its findings can be generalized to encompass other medical conditions and healthcare settings. Consequently, the study's conclusions are circumscribed in their applicability. Subsequent research endeavors should adopt a more expansive perspective, exploring the systemic viewpoint across a spectrum of diseases and pathways. Additionally, the study's research questions predominantly revolve around identifying the fundamental principles and concepts of the systemic perspective and their implications for communication strategies. While this theoretical exploration is enlightening, these inquiries tend to overlook practical implementation. Future research should seek to strike a balance between theoretical underpinnings and practical considerations, ensuring that the insights derived are not only theoretically robust but also operationally relevant.

7.2 Method: attrition, virtual interviews, and dual perspectives

One methodological constraint (S4-S11 in SRQR) arises from the utilization of the longitudinal patient mapping technique, which entailed an exploration of all contact points within individual medical histories (O'Brien et al., 2014). This technique inadvertently introduces a potential concern related to inducing a state analogous to "sickening," where patients are recurrently confronted with reminders of their illness. This unintended emotional discomfort likely contributed to the voluntary withdrawal of four patients from the study. To mitigate this issue, a multifaceted approach was adopted, involving not only patients but also their next-of-kin and attending physicians, with the aim of alleviating the emotional burden and enhancing participation. Furthermore, the implementation of customized

reporting methods (e.g., offering the diary template via email or traditional postal services), was made available to accommodate participants and ensure their comfort throughout the research process.

The notable dropout rate observed in the study, which was likely influenced by a demanding workload on participants and clinical complications, brings forth pertinent questions concerning the suitability of the research design, particularly when considering individuals coping with chronic or severe medical conditions. This observation underscores the imperative need to consider the substantial physical and emotional demands imposed on study participants, especially in research projects involving extended data collection periods. Furthermore, the research's sampling strategy, primarily predicated on the availability of participants and restricted by the constraints of a limited sample size, introduced potential vulnerabilities to the overall reliability of the study (Clark et al., 2021). Consequently, it becomes imperative to cultivate an understanding of the underlying determinants that precipitate participant attrition, especially when working with a relatively modest cohort. This necessitates a thorough investigation into the multifaceted factors contributing to participant attrition and, if deemed applicable, the formulation of prospective strategies to mitigate these issues in future research endeavors. Such undertakings should proactively confront these methodological challenges and implement strategies designed to mitigate participant dropout rates.

7.2.1 Virtual interviews on Teams

An inherent limitation in the methodology pertains to the utilization of virtual interviews conducted through the Microsoft Teams platform. It became evident during the course of these interviews that few healthcare professionals and patients occasionally encountered suboptimal audio or visual conditions. These conditions had the potential to result in the inadvertent omission of questions or less distinct responses, thereby posing a risk of incomplete data acquisition. In response to this constraint and with the aim of enhancing internal validity and data reliability, critical measures were instituted to gain a more profound understanding of patient pathways in the context of neurological diseases (Merriam & Grenier, 2019). During the interview sessions, efforts were made to enunciate questions clearly and repeat them when necessary to ensure that participants fully comprehended the inquiries. Additionally, attention was given to the process of verbatim transcription and review of all interview recordings. These steps were taken with a dual purpose in mind, first, to enable inductive data analysis, and second, to alleviate the potential constraints associated with virtual interviews, thereby reinforcing the methodological rigor underpinning this study.

7.2.2 Coordinators' perspectives

In the context of in-depth interviews, the study employed a deliberate and strategic approach aimed at assembling a diverse cohort of interviewees, thus encompassing clinicians and coordinators. This strategic selection was motivated by the objective of obtaining a multifaceted perspective of healthcare management and communication. Care was taken to avoid unwarranted generalization of the viewpoints expressed by coordinators, often situated at a remove from direct clinical activities. Instead, their insights were thoughtfully integrated with data gleaned from clinicians. This method was

chosen to construct a nuanced portrayal of the service provision landscape. Such caution arises from an appreciation of the distinct roles that coordinators typically occupy within the healthcare settings. In contrast to clinicians, deeply enmeshed in medical practice, coordinators often held administrative positions with limited direct patient interaction. These discrepancies in professional experience and clinical exposure can potentially influence the depth and breadth of information conveyed during interviews. Therefore, this limitation underscores the necessity of interpreting and contextualizing the perspectives articulated by coordinators within the broader framework of data derived from diverse sources.

7.3 Results: a journey unwished for

Upon a thorough exploration of the limitations unearthed by the study's theoretical findings, it becomes imperative to scrutinize a fundamental distinction within healthcare (S12-S14 in SRQR) (O'Brien et al., 2014). These constraints are intrinsically rooted in the lineage of the user journey literature, as seen in the longitudinal mapping of patient journeys. This lineage may disregard the broader societal, ethical, and public health dimensions that inherently underpin the healthcare setting. In contrast to the domains of commerce, wherein patrons proactively seek and willingly partake in service experiences, patients frequently find themselves involuntarily and reluctantly propelled into arduous trajectories necessitated by compelling medical exigency. The depiction of a patient's passage through the ecosystem as a "journey" may inadequately encapsulate the multifaceted nature of encounters, characterized by ethical considerations, the nuanced complexities of clinical expertise, the labyrinthine schema of regulations, and the overarching imperatives of public welfare. It is crucial to recognize that patients do not embark on these trajectories by choice, rather, they are compelled by the urgent need to address health-related concerns, profoundly influenced by relative factors (e.g., medical necessity, professional guidance, and institutional protocols).

Significantly, individuals coping with neurological diseases frequently contend with intense feelings of dependency and vulnerability as they grapple with the profound imperative of restoring their health and overall well-being. This overarching goal markedly diverges from the pursuit of the memorable service experiences often underscored in commercial contexts. Therefore, the focal point extends far beyond the customary realm of mere customer satisfaction, embracing a broader spectrum of considerations, most notably patient outcomes and the delivery of compassionate care. Of paramount importance are the emotional and psychological dimensions that typify the experiences of chronically ill patients. They consistently confront intense emotions, encompassing, among others, fear, anxiety, and uncertainty throughout their journey. Their encounters frequently involve decision-making processes, invasive medical procedures, and the formidable responsibility of proactively managing their conditions. Ironically, SDL, despite its roots within the marketing discipline, strategically harnessed to confront these contextual challenges, has unveiled a shift in perspective. The embrace of systemic interconnectedness and recognition of interdependencies underscores the notion that the

patient experience transcends the conventional boundaries of marketing contexts. In essence, the adoption of SDL served as a potent catalyst for reimagining the patient's character within the healthcare ecosystem and emphasized the compelling shift towards more holistic and patient-centric models.

7.4 Discussion: overcoming GDL influence

A noteworthy limitation encountered in the alignment of theoretical findings with empirical data (S15-S19 in SRQR) pertains to the potential influence of inadvertent leaning towards Goods-Dominant Logic, despite having conducted an extensive literature review on SDL (O'Brien et al., 2014). As a fledgling researcher deeply engaged in this field, it is crucial to acknowledge that pre-existing knowledge and perspectives can inadvertently shape the interpretation and analysis of data, potentially impinging upon the discussion section of the study. This inclination towards GDL thinking can be attributed to prior exposure and familiarity with traditional goods-centric paradigms prevalent across diverse domains. The inherent biases and assumptions associated with GDL may unconsciously underpin the conceptualization and analysis of the research subject, even when a concerted effort is made to embrace an SDL lens. The concept of reflexivity necessitated continual self-awareness and introspection to ensure an open and unbiased approach in the study's discussion. Furthermore, the practice of seeking peer debriefing and soliciting feedback from a supervisor well-versed in SDL proved instrumental in providing constructive perspectives. This facilitated a critical evaluation of interpretations and served as a safeguard against significant predispositions. Nevertheless, it is imperative to note that despite the proactive measures taken to curtail the influence of GDL thinking, complete eradication of this influence may not be entirely attainable.

7.5 Avenues for future research

In the realm of future research, current scholarship within the framework of SDL exhibits a conspicuous tendency to concentrate its intellectual gaze primarily on select industries, often tethered to the realms of pleasure and leisure (e.g., travel and hospitality). However, as the collective pursuit of advancing the theoretical and pragmatic foundations of the systemic perspective remains paramount, a compelling imperative arises to expand the horizons of these investigative endeavors. This expansion necessitates a deliberate diversification of scholarly exploration, entailing a systematic examination of quotidian services that, despite their lack of inherent connotations of delight and gratification, constitute indispensable components of human existence (e.g., filing tax returns, navigating the labyrinthine corridors of the criminal justice system, negotiating the logistical intricacies of urban parking, or traversing the bureaucratic channels involved in securing a nursery place for one's child). Through the orchestration of academic inquiries into these unassuming yet pivotal domains, researchers are poised to unearth a rich tapestry of observations emblematic of the dynamics that define human interactions with these services. This nuanced extension of research into contexts that

may lack the allure of traditionally favored domains, but nevertheless represent foundational pillars of essential services, holds the potential for facilitating an exhaustive exploration of the multifaceted dynamics characterizing human interactions with these service provisions. Within the intricate tapestry of these service domains, researchers are at the precipice of uncovering the subtle yet critical aspects of user journeys (e.g., identifying the pain points, surmountable challenges, and occasional success stories). The knowledge distilled from such endeavors assumes the form of invaluable assets, capable of informing the decisions and actions of policymakers, service providers, and designers.

Armed with a profound comprehension of these nuanced service interactions, these actors are positioned to embark on a journey of strategic refinement, one predicated on the principles of simplification and streamlining. Such strategic enhancements are conceived with a dual purpose, that is encompassing the alleviation of user frustration and the reduction of temporal inefficiencies. Both facets contribute to an overarching enhancement in the efficacy and efficiency characterizing the services under examination. Consequently, this concerted effort is designed to appease immediate user journey concerns while also enhancing the overall performance and delivery of services, ushering in a more proficient service environment.

This broadened research ambit within the sphere of SDL serves as a fundamental catalyst for the advocacy of social equity and the fostering of inclusive design principles. The barriers encountered by individuals with disabilities, those navigating the complexities of language disparities, or individuals hailing from a myriad of culturally diverse backgrounds as they engage with indispensable services emerge into the spotlight of scholarly inquiry. This heightened awareness and nuanced understanding of the intricate challenges faced by these user groups give rise to a compelling imperative for the implementation of equitable design strategies and policy adjustments. Such endeavors are purposively geared towards the establishment of unfettered access to these essential services, with a commitment to impartiality and fairness, irrespective of an individual's demographic attributes. This trajectory underscores a profound commitment to transcending societal disparities and ensuring that vital services are universally accessible and user-friendly.

In conclusion, the integration of SDL research into atypical yet fundamental service contexts underscore its capacity to elevate service quality, streamline user experiences, and fortify the tenets of social equity and comprehensive design. This scholarly trajectory champions a holistic approach to user-centered design, wherein the optimization of both pleasurable and necessary interactions accrues benefits to individuals and society as a collective entity. This avenue of SDL research unravels novel horizons, presenting scholars and practitioners with an array of diversified service contexts, ripe for exploration concerning the applicability and implications of the systemic principles.

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List of appendixes

APPENDIX A: TABLE RELATING SDL AND PATIENT PATHWAYS

RELATING THE REVIEWED LITERATURE	
SERVICE-DOMINANT LOGIC	PATIENT PATHWAYS
<p>Larger service ecosystem <i>“Service ecosystems are, however, also often nested within or are part of another, larger service ecosystem”</i> (Lusch & Vargo, 2014, p. 163).</p>	<p>Wider public service system <i>“[...] can extend to the wider public service system (e.g. housing, education, benefits) which can assist the general well-being and independent living of patients and their relatives”</i> (Williams & Radnor, 2022, p. 1137).</p> <p><i>“[...] connect the local system to the larger whole</i> (Aarhus et al., 2019, p. 3).</p> <p><i>“Proposition one [of the SERVICE framework] refers to public service organisations being part of complex service delivery systems [...] In the UK and elsewhere, there are continual calls for better joined-up healthcare services”</i> (Williams & Radnor, 2022, p. 1129).</p> <p><i>“The critical sensemaking perspective, introduced by Mills et al. [46] and elaborated further by Aaroma et al. [47], provides a framework for understanding how individuals make sense of their environments at a local level while acknowledging the societal context [...] Critical sensemaking positions the context as a link between dominant social values and individual action”</i> (Torseth & Adnanes, 2022, p. 3).</p> <p><i>“Crossover of care is a key element of patient care pathways, hence ‘thinking process’ provides an opportunity to picture individual processes, their connections and links with associated processes and how they fit into the whole care process”</i> (McCracken & Edwards, 2017, p. 10).</p> <p><i>“Frontline professionals are socially embedded in society –that is, they depend on the nested social arrangements that extend beyond their professional community[...] the autonomy perspective tends ‘not to consider the wider ecological context”</i> (Wilhelm et al., 2020, p. 1192).</p>
<p>Open system <i>“Therefore, the enterprise is relatively unbounded or part of an open system because it cannot separate itself from the society within which it is embedded. The reason this matters is that managing a closed system is different from “managing” an open system. The latter is more of an iterative, effectual process, in which actors operating in an open system riddled with uncertainty cannot predict the future but can take actions that effect it, a step or two at a time”</i> (Lusch & Vargo, 2014, p. 22).</p>	<p>Environmental dynamics <i>“The COVID-19 pandemic has induced changes within the healthcare system, and it is only with better appreciation for the impacts of these changes that further modifications can be integrated into patient care to create a suitable healthcare environment for a postpandemic world[...] broader dynamics of the healthcare pathways”</i> (Bernacki et al., 2021, pp. 1-2).</p> <p><i>“[...] clinical and organizational issues related to COVID-19 has led all levels, operating in a context of radical uncertainty [...]”</i> (Foglia et al., 2022, p. 2).</p> <p><i>“COVID-19 is destabilizing the foundations of healthcare”</i> (Bernacki et al., 2021, p. 3).</p> <p><i>“In busy, dynamic work environments [...]”</i> (O'Brien et al., 2015, p. 2).</p> <p><i>“This increased connectivity or ‘intertwinement’ of professions and organisations is described in the literature on ‘organised professionalism”</i> (de Bont et al., 2016, p. 2).</p> <p><i>“[...] healthcare systems transform (some accelerated by the Covid-19 pandemic) [...]”</i> (Williams & Radnor, 2022, p. 1129).</p> <p><i>“The maturity and experience of the [community healthcare] team assists in creating a stable environment and embedding the service within the wider organisation”</i> (Williams & Radnor, 2022, p. 1137).</p>

“The findings resonate with Schön’s early work (1973) on social change and the loss of stable states within organisational change. In particular how the individual(s) in the midst of a change processes must learn to transform themselves and learn how to adapt and change” (Anderson et al., 2014, p. 165)

“[...] in the dynamic environment of a hospital. This is chiefly influenced by legal regulations and medical progress. The constantly changing factors influencing process management exert pressure on the hospital to adapt and change, to which it must respond suitably (Feyrer et al., 2006, p. 96)”.

“Within hospitals, although care processes largely stay consistent, the environment itself is dynamic and fast moving” (McCracken & Edwards, 2017, pp. 5-6).

“[...] complex, adaptive hospital system” (Wackers et al., 2021, p. 1).

“Health care system is faced with challenges and opportunities from a rapidly changing operating environment” (Camgoz-Akdag et al., 2017, p. 780).

“This approach [sensemaking perspective] comprehends sensemaking as a holistic practice where the context and environment are integral” (Torseth & Adnanes, 2022, p. 3).

“The constantly changing factors influencing process management exert pressure on the hospital to adapt and change, to which it must respond suitably” (Feyrer et al., 2006, p. 96).

Multi-level in nature

«Service ecosystems should not be viewed as one-dimensional or flat, micro-level structures of interacting and service-exchanging actors. Rather, service ecosystems are multi-level in nature. From the micro system a meso system emerges and from the meso system a macro system emerges. In turn, the macro system filters its way down to meso and micro systems and hence influences the actors in these systems” (Lusch & Vargo, 2014, p. 169).

System levels

“The newly developed clinical pathway was set up as a modular system with an increasing degree of detail (macro level, meso level, and micro level)” (Feyrer et al., 2006, p. 92).

“The patient journey mapping tools have assisted them, and their colleagues, to identify practice issues, communicate them effectively, and seek strategies at personal, professional, organisation, and system levels” (Kelly et al., 2017, p. 541).

“Authors created and used a novel patient journey map focused on improving continuity of care and safety at a health systems level” (Ludwiczak, 2021, p. 30).

“Batalden & Splaine (2002) advocate a process view of health care provision with an emphasis on what they describe as microsystems (a group of people that are involved in the care of an individual patient)” (McCracken & Edwards, 2017, p. 4).

“Resistance to change may arise at micro (individual), meso (organization), and macro (policy) levels” (Rizan et al., 2020, p. 208).

“An organizational-level situational characteristic affecting care pathway enactment is the collective level of professional expertise in a department” (Wilhelm et al., 2020, p. 1175).

“The challenge of pathway mapping is to provide both a highlevel view that illustrates the whole care system and the detail of specific activities” (Mould et al., 2010, p. 2).

“[...] healthcare at a micro-level [...] at a macro-level [...]” (Matthias & Brown, 2016, p. 1435).

“[...] further developed the EPJB using a high-level process map for a standard in-patient journey” (Clark et al., 2014, p. 261).

“[...] hospital and network level [...]” (O’Brien et al., 2015, p. 3).

“As described in conceptual studies, journey maps offer a perspective that takes into account the more dynamic and multidimensional aspects of healthcare interactions to facilitate enhanced insight into the patient experience within medical research” (Ly et al., 2021, p. 7).

“In conceptual terms, this emphasizes the need for a multidimensional and multilevel model of “process” management; a perspective that exists in the (H)OM literature but is not widely deployed” (Frangeskou et al., 2020, p. 1194).

“In Norway, mental health services are public and organized in tandem with general health services at the municipal level and specialist level” (Torseth & Adnanes, 2022, p. 4).

“EPJBs [electronic patient journey boards] can be structured to present data at multiple levels, from the unit, department, service, organisation to system levels, facilitating an open dialogue with senior leadership, because they can also view individual wards’ EPJBs at any time” (Clark et al., 2014, p. 263).

“In her conceptual work, Bechky (2011, p. 1157) emphasizes that coalface research should incorporate ‘the social processes that take place at different levels of organizational life’ by seeking ‘to interconnect those multiple sets of activities’ [...] Studying these situational dynamics and the link between micro-level practices and macro-level influences, as well as their consequences, will advance the processual nature of frontline professional work” (Wilhelm et al., 2020, p. 1193).

“[...] at all levels of the organization” (Wackers et al., 2021, p. 5).

“Hence, an important question is whether extended role development confines itself to these local practices, or whether the extended roles will find their ‘way up’ to the level of professional associations, educational programs and policy level, leading to formal changes in professional jurisdictions” (de Bont et al., 2016, p. 12).

Tiers of service providers

“A supply network structure involves tiers of service providers from first-tier direct interactions to second-tier and beyond indirect interaction and similarly multiple tiers of service beneficiaries” (Lusch & Vargo, 2014, p. 160).

Primary, secondary and tertiary care

“The NHS operates in a broadly similar way to other health systems in that it is split up into two main divisions: the first division is responsible for strategy, policy and management, and the other deals with the provision of actual medical and clinical care (Grosios et al., 2010). The latter includes primary care (e.g. general practitioners, dentists and pharmacists), secondary care (e.g. hospitals) and tertiary care (e.g. specialist hospitals)” (Ponsignon et al., 2018, p. 2334).

“Australia has a world-class healthcare system with publicly funded primary, secondary and tertiary care, accessible to all citizens” (Kelly et al., 2017, p. 536).

“care nurse consultants across two palliative care inpatient units within a major tertiary hospital network in Melbourne, Australia” (Ly et al., 2021, p. 3).

“The study took place in the Diabetes Day Centre, an outpatient unit in University Hospital Galway part of the GRUHG, a tertiary referral centre in the West of Ireland with over 67 000 outpatient consultations annually” (McDermott et al., 2013, p. 682).

“Streamlining an existing hip fracture patient pathway in an acute tertiary adult Irish hospital to improve patient experience and outcomes” (Murphy et al., 2019, p. 45).

“Zimbabwe delivers the primary health care with welltrained HCWs [health care workers] at the lowest level of care to manage the most common diseases affecting the local population” (Chirenda et al., 2021, p. 9).

“Strategic direction is formally developed in July-December each year by NHS [National Health Service] England (which commissions primary care), the CCGs [clinical commissioning groups] (who commission all other care) and local authorities (who

commission social care) to plan services over a five-year horizon” (Matthias & Brown, 2016, p. 1444).

“[...] responsibilities from national level to district health care workers [...]” (Chirenda et al., 2021, p. 12).

“[...] employees working in the primary care process [...]” (Veld & Alfes, 2017, p. 2305).

“Care is delivered in primary and secondary settings” (de Bont et al., 2016, p. 3).

Zoom out

“The idea of zooming out from the dyadic exchange and chains of dyadic exchange to a service system offers a unifying perspective of markets, service, and exchange systems in general and hence in society” (Lusch & Vargo, 2014, p. 159).

Broader perspective

“Some pathway models aim for a very precise definition of the activities, as required when specifying an engineering system; others place a greater emphasis on communicating a systemic vision to a wider audience” (Mould et al., 2010, p. 1).

“A much more holistic approach in providing a full service for the whole of the patient journey is needed” (Matthias & Brown, 2016, p. 1435).

“Burgess and Radnor’s (2013) study of English NHS Hospital Trusts reported a movement from project-based improvement to more systemic change” (Williams & Radnor, 2022, p. 1128).

“For patients, caregivers, and HCPs alike, the social, political, and cultural implications of the pandemic have changed the attitudes, beliefs, and behaviors toward the healthcare system and pushed them outside their previously narrow framework” (Bernacki et al., 2021, p. 7).

“Engagement should also be broadened towards relevant stakeholders outside the hospital.³⁴ Engaging hospital partners has been key for success” (Wackers et al., 2021, p. 7).

“However, further research (and probably development work in hospitals) can be carried out to provide a broader perspective around, for example, the extent pharmacy influences the length of stay of a non-elective inpatient” (Matthias & Brown, 2016, p. 1149).

“In comparison to conventional medical records, journey maps link patient healthcare encounters longitudinally, promoting continuity and a holistic understanding of care across settings and over time” (Ly et al., 2021, p. 7).

“Taking a more holistic view of the service process also contributes to quality and patient satisfaction which are part of the outcome measures in health care” (McCracken & Edwards, 2017, p. 3).

Systemic view

“We have found the systems concept is more amenable to the dynamic service exchanges that are so central to S-D logic” (Lusch & Vargo, 2014, p. 161).

Whole systems approach

“First, the whole systems approach is common to the supply chain context required for sustainable improvement” (Williams & Radnor, 2022, p. 1132).

“The experience demonstrated the value of the pathway in providing: a more systemic appreciation of care activities; better communication and a shared understanding of the current organisation of care; a means of comparing practices; a tool for analysing the current system; a focus for debating changes to current practices” (Mould et al., 2010, p. 5).

“[...] it’s a whole system approach” (Matthias & Brown, 2016, p. 1445).

“Rothschild et al (2005), also advocate a system-oriented perspective to assist in the improvement of the delivery of health information systems, particularly within acute Care” (McCracken & Edwards, 2017, p. 4).

“For those public administration offices that apply continuous process improvement, for example as part of the lean management concept or systemic quality management, it can support the analysis of processes [...]” (Ludwiczak, 2021, p. 31).

“[the hospital strategy development is] A whole system approach – national and local, immediate and the 7-year forward view – sets the ambition and the direction” (Matthias & Brown, 2016, p. 1448).

“Worldwide, healthcare systems [...] the context of universal healthcare systems” (Williams & Radnor, 2022, p. 1126).

“[...] the systemic working of the team was certainly prominent in our data” (Williams & Radnor, 2022, p. 1139).

Complexity exchange systems

“And all actors are connected directly to other actors and resources and indirectly to a network or system of other actors and networks that are increasingly removed but tied together through an intricate web of relationships or complex exchange” (Lusch & Vargo, 2014, p. 113).

Complexity of healthcare services

“As argued by Day and others (Andersen & Aarhus, 2017; Day, Coombes, McGrath-Lone, Schoenborn, & Ward, 2017), the escalating complexity of health care impinges on service delivery, engendering fragmented care trajectories and patient transition issues” (Aarhus et al., 2019, p. 1).

“This [current state map] permitted the complexity of the patient flow through the clinic to be visualised” (McDermott et al., 2013, p. 682).

“A care pathway is a complex intervention for the mutual decision-making and organisation of care processes for a well-defined group of patients during a well-defined period”(Schrijvers et al., 2012, p. 1).

“In healthcare, flow orientation is challenged by complex care processes that involve multiple healthcare units or teams; when multiple teams are involved, individual staff members frequently do not experience the entirety of the patient journey or the work process, and it may be difficult to identify who should take responsibility for the complete patient flow” (Murphy et al., 2019, p. 49).

“Aboriginal patient journeys from home to hospital are often complex involving multiple care providers and settings” (Kelly et al., 2017, p. 537).

«Effective management of discharge requires a planned and coordinated approach involving early identification of patients with complex needs and multidisciplinary involvement to formulate a plan to address these needs» (Clark et al., 2014, p. 263).

“[...] the multifaceted nature of the healthcare processes [...] manage the dynamic and complex nature of healthcare processes” (Frangeskou et al., 2020, p. 1195).

“Healthcare organisations particularly face this challenge of operating within complex service systems where many patients have comorbidities and complex needs” (Williams & Radnor, 2022, p. 1129).

“It [journey mapping] is gaining increasing recognition for its ability to organise complex multifaceted data from numerous sources and explore interactions across care settings and over time” (Ly et al., 2021, p. 2).

“This study was conducted at the Complex Operative Unit (UOC) of Orthopedics and Traumatology of the University Hospital ‘Federico II’, one of the largest and most complex health care facilities in Southern Italy” (Improta et al., 2015, p. 663).

“Complex bureaucratic procedures resulting in compilation and communication errors among users involved in the process” (Improta et al., 2015, p. 668).

“The complexity of the map made it difficult to identify redundant tasks; the flow of information could not easily be distinguished from the flow of the patient, nor could categories of patients be differentiated” (Mould et al., 2010, p. 3).

“[...] driven by the ever increasing complexity of healthcare services due to medical technological and clinical knowledge development” (de Bont et al., 2016, p. 11).

“In addition, cancer patients are particularly involved in their healthcare experience as the healthcare process is still complex and poorly coordinated” (Cherif et al., 2020, p. 2).

“An IPO [Input Process Output] process map is a visual representation of a process, frequently used in multifaceted or complex [healthcare] processes to facilitate identification of critical process steps required to facilitate inputs evolving to outputs” (Murphy et al., 2019, p. 47).

“Health-care organisations and in particular hospitals are large and have a complex structure” (McCracken & Edwards, 2017, p. 2).

“The authors highlight the multi-faceted nature of design and delivery of a multi-touchpoint service within the complexity of a large healthcare provider” (Matthias & Brown, 2016, p. 1435).

“Hospitals have grown into large and increasingly complex organizations” (Wackers et al., 2021, p. 1).

“Acknowledging the multifaceted nature of cancer care delivery [...]” (Aarhus et al., 2019, p. 6).

A self-sustaining system

“A service ecosystem is a relatively self-contained, self-adjusting system of resourceintegrating actors that are connected by shared institutional logics and mutual value creation through service exchange” (Lusch & Vargo, 2014, p. 161).

Organisational sustainability

“[...] considers the environment and how service organisations embrace and embed organisational sustainability. The sustainability of individual organisations is a prerequisite for the long-term survival of the wider system of public services (Williams & Radnor, 2022, p. 1129).

“[...] to engender long-term sustained cultural and behavioural change [...]” (Matthias & Brown, 2016, p. 1450).

“[...] streamlined pathway will only become embedded and self-sustaining once a critical mass of individuals has been convinced of the merits of change” (Rizan et al., 2020, p. 207).

Network

“In S-D logic, dyads exist, but embedded in triads of actors that form a network” (Lusch & Vargo, 2014, p. 159).

Health network

“[...] “networks”, like healthcare” where many tasks are processed by indivisible (human or otherwise) multitasking resources” (Frangskou et al., 2020, p. 1179).

“The creation of networks of coordinated health actors such as cancer networks must be a priority for hospitals” (Cherif et al., 2020, p. 9)”.

“The hospital exists as part of a local health network with two other smaller hospitals” (O'Brien et al., 2015, p. 1).

“[...] major tertiary hospital network” (Ly et al., 2021, p. 3).

“[...] physician to the respective pathway in the internal network” (Wilhelm et al., 2020).

“Collectively, the HD [Huntington’s disease] team has considerable knowledge of the wider health and social care system/network and were actively able to support and signpost their patients” (Williams & Radnor, 2022, p. 1139).

“However, as more actors interact with one another through many-to-many networks, their actions and interactions change the context of other actors, increasing the dynamics and turbulence” (Lusch & Vargo, 2014).

Process networks

“In the service ecosystem all actors are part of many processes” (Lusch & Vargo, 2014, p. 170).

Process orientation

“Edwards et al (2005) argue that the application of a process view of KM [knowledge management system] within health care would give a better overview of the whole care process, allowing the knowledge needs of all stakeholders to be met” (McCracken & Edwards, 2017, p. 4).

“From this theoretical perspective, the SDS [service delivery system] design is concerned with the configuration of operational resources and processes to support the realisation of a successful experience at all stages and points of customer contact” (Ponsignon et al., 2018, p. 2329).

“Batalden & Splaine (2002) advocate a process view of health care provision with an emphasis on what they describe as microsystems (a group of people that are involved in the care of an individual patient)” (McCracken & Edwards, 2017, p. 4).

“The results of this investigation demonstrate that computerized simulation of treatment processes can make a valuable contribution to process optimization in the hospital” (Feyrer et al., 2006, p. 97).

“McDermott and Venditti, (2015) found that through the process and value stream mapping, healthcare professionals were able to understand the nature of the process and how their tasks fit together” (Frangeskou et al., 2020, p. 1180).

“[...] the basic principles indicate the use of a process approach and customer orientation. This means that they should measure, analyze and improve processes in order to fully meet the needs and expectations of customers” (Ludwiczak, 2021, p. 22).

“The aim is to redesign care adopting a process-orientated system, with the main focus on the needs of the patient as represented in the pathway” (Mould et al., 2010, p. 1).

“[...] pertinent to today’s healthcare environment [...] ;process management” (Matthias & Brown, 2016, pp. 1438-1439).

“For example, in 2010, a review of the use of business process improvement methodologies in the public sector reported 51% of publications focused on lean, with 35% of these being in health services” (Williams & Radnor, 2022, p. 1128).

“Moreover, resources sharing (especially in public-service models like the UK NHS) can have strongly p(P)olitical dimensions (Grove et al., 2010). Drupsteen et al. (2016) show that an over-arching emphasis on resource utilization can create conflict between “resource-providing” departments (such as radiology), focussed on meeting their own performance targets and the “resource-deploying” care pathways” (Frangeskou et al., 2020, p. 1180).

“Therapeutic-Assistance Path (DTAP) can be considered clinical-organizational management tools that define the best sequence of clinical assistance actions aimed at patients, developed in accordance with the principles of Continuous Improvement, focusing on process management based on available evidence” (Improta et al., 2019, p. 4).

“[...] processual nature of frontline professional work” (Wilhelm et al., 2020, p. 1193).

«In a process-oriented organisation, processes are mapped so that task responsibilities are described with a focus on processes. This form of responsibilities exceeds the functional borders and encourages all members of the different departments to collaborate and achieve common goals. It also implies the use of process-oriented performance indicators,

obliging the members of an organisation to work together as one group» (Gemmel et al., 2008, p. 1209).

Managing processes

“A common problem in managing service processes is that enterprises design work-around functions that actors perform rather than service that other actors receive” (Lusch & Vargo, 2014, pp. 171-172).

Disconnection between healthcare providers

«The process perspective provides an especially useful framework for addressing a common organisational problem: fragmentation or the lack of functional integration” (Gemmel et al., 2008, p. 1209).

“It also revealed areas of poor quality staff–staff interactions, unnecessary travelling within the department, re-work and bottlenecks” (McDermott et al., 2013, p. 682).

“The ability for clinicians involved in adjacent connecting specialities to share knowledge provided clear benefits for patients” (McCracken & Edwards, 2017, p. 9).

“Statements that treatment involving multiple departments suffer from a higher risk of coordination problems, resulting in treatment error” (Wilhelm et al., 2020, p. 1182).

“Patient care is delivered through a collection of professional specialists who operate in distinct, hierarchical arrangements across organisational units. The delivery of care is thus said to be fragmented” (McCracken & Edwards, 2017, p. 2).

“Periodically, scholars call for more operations management research in not-for-profit and public sector organisations (Karwan and Markland 2006; Taylor and Taylor 2009), because increasingly the fragmented and interorganisational context of public services delivery” (Williams & Radnor, 2022, p. 1127).

“During the last decade, there has been a transition from viewing the company as a number of departments to focusing on the business processes being performed.” (Gemmel et al., 2008, p. 1208).

“[...] healthcare systems increasingly fragmented and complex to navigate” (Aarhus et al., 2019, p. 1).

«The other element of sustainability to be considered is (health) service sustainability, in particular the need to move away from service silos to create an integrated service. To some extent, the multidisciplinary nature of the team and the collaborative working environment have enabled them to blur the professional boundaries that might be more evident in clinical teams» (Williams & Radnor, 2022, p. 1137).

“From a historical point of view, hospitals are considered as a collection of professional functions, brought together to care for, and later cure, the patients. In this way it is not surprising that historically these hospitals were organised along functional departments” (Gemmel et al., 2008, p. 1209).

“Healthcare services are often criticised for lack of coordination and joined-up care” (Williams & Radnor, 2022, p. 1130).

“Examples of waste include unnecessary process steps, avoidable movement of people and goods, unnecessary waiting time (due to lack of coordination between processes)[...]” (Rizan et al., 2020, p. 202).

“McDermott and Venditti (2015) found that professionals sometimes do not know what happens after they perform their tasks and how their tasks fit within the overall flow. van Leijen-Zeelenberg et al. (2015) ascribed communication failures in six acute care hospital pathways to limited shared understanding of the overall pathway” (Frangeskou et al., 2020, p. 1180).

“Processes are generally independent of formal organisational structures, crossing functions or departments and involving people with different expertise and roles. However, formal organisational structures can strongly influence the effectiveness of processes” (Gemmel et al., 2008, p. 1208).

“The term “integrated care pathway” is longer than necessary. Care pathways (as defined above) are per definition integrated. Fragmented care pathways cannot exist” (Schrijvers et al., 2012, p. 2).

“Professional “silos” fragment care (Mann, 2005) and increased pressure to improve specific aspects of in silo performance results in worse system level outcomes” (Frangeskou et al., 2020, p. 1180).

“This [networking skills] develops a cultural change to the current silo working, which precludes effective pathway management, and begins the journey of integrated and patient-focussed service delivery, as advocated by Lean thinking” (Matthias & Brown, 2016, p. 1449).

“A typical hospital tends to be structured departmentally according to medical specialities with their focus internal – functional silos (Edwards, 2011). Clinicians however need to be able to share knowledge regarding patients across various speciality departments and processes, following a patient along a care pathway. Business processes typically cut across organisational boundaries, consequently boundary spanning knowledge needs to be provided across the organisational silos” (McCracken & Edwards, 2017, p. 3).

“An identified barrier in implementation [of a reorganization] is a lack of coordination between projects and departments” (Wackers et al., 2021, p. 7).

“There were no themes which identified they had moved into a seamless state of team working” (Anderson et al., 2014, p. 164).

“Although each of the four individual teams involved in delivering hip fracture care in the hospital may have worked well in and of themselves, the broader vision of the four teams together forming a single larger team in the delivery of hip fracture care was absent. Each individual team worked to deliver their segment of the care pathway, but there was limited communication, and hence integration of care across the teams” (Murphy et al., 2019, p. 49).

“The other element of sustainability to be considered is (health) service sustainability, in particular the need to move away from service silos to create an integrated service” (Williams & Radnor, 2022, p. 1137).

“However, this [Australian healthcare] system operates in silos, with poor interservice communication and significant coordination gaps. Generally, there are no designated health professionals or support persons to coordinate the entire patient journey from home to hospital to home” (Kelly et al., 2017, p. 536).

“In addition, cancer patients are particularly involved in their healthcare experience as the healthcare process is still complex and poorly coordinated” (Cherif et al., 2020, p. 2).

Integration of resources

“What is revealed is a society that is a very large-scale service ecosystem cocreating value through resource integration and service exchange” (Lusch & Vargo, 2014, p. 205).

Integrated pathways

“The integrated governance of these organisations is insufficient to support the level of integration needed for complex systems.” (Williams & Radnor, 2022, p. 1129).

“Connecting across the service provision (and care supply chain) to help deliver an integrated service. Examples of working across healthcare and social care [...] One element of embedded organisational sustainability is the continuity of the team members and ensuring any new members are properly inducted and well versed in the systems supporting the HD [Huntington’s disease] service” (Williams & Radnor, 2022, p. 1140).

“[...] thus going some way towards integrating care and service delivery, and providing patient-centred hospital performance” (Matthias & Brown, 2016, p. 1149).

“[...] by the integration of the skills of the various professional figures [...]” (Improta et al., 2019, p. 3).

“Co-ordination and integration of care is one of the identified dimensions of patient-centred care and is integral to efficient patient flow [29]. Staff engagement and improved inter-team working were integral to the success of the process redesign; specifically, communication and co-ordination of care between the ED, orthopaedic, orthogeriatric and anaesthetic teams were improved, resulting in a more streamlined and more integrated care pathway” (Murphy et al., 2019, p. 49).

“A good example are the integrated cancer care pathways, established in 2009 and based on the in previous years established multidisciplinary guidelines for doctors, nurses and other professionals” (Schrijvers et al., 2012).

“[...] make best possible use of public resources to deliver a public service” (Matthias & Brown, 2016, p. 1438).

“Effective management of discharge requires a planned and coordinated approach involving early identification of patients with complex needs and multidisciplinary involvement to formulate a plan to address these needs” (Clark et al., 2014, p. 263).

“Integrating diverse components of the patient healthcare journey provides a holistic perspective of the relationships between the different elements that may guide directions for change and service improvement” (Ly et al., 2021, p. 2).

“Complete integration may improve the use of pilots’ knowledge and skills, as well as enable them to build the required resources (i.e. relationships etc.) to manage the dynamic and complex nature of healthcare processes” (Frangeskou et al., 2020, p. 1195).

“Tay et al. (2017) stated that if the focus of a system is on maximizing resource efficiency, without reflecting on how the specific resources interact with the other elements of the system, then, this will eradicate the resource efficiency outcome of the whole system” (Frangeskou et al., 2020, p. 1179).

“Integrated care optimizes patient pathways across organizations, coordinating efforts of hospitals, primary care and long-term care in networks or integrated organizations” (Wackers et al., 2021, p. 2).

“As described in Boissevain's (1974) Mediterranean studies, the objective of brokers [case managers] is to exchange their resources, that is, strategic contacts and relationships, into resources that can help the people they work with obtain their goals” (Aarhus et al., 2019, p. 3).

Interactive view of resources

“In summary, many ideas on resource scarcity are based on a static view of resources” (Lusch & Vargo, 2014, p. 125).

Resource scarcity

“[...] the challenge for healthcare providers to offer the best possible service within pre-determined resources is universal” (Matthias & Brown, 2016, p. 1450).

“[...] care processes in limited-resource public health” (Chirenda et al., 2021, p. 15).

“Similarly, Elissen et al. (2011) found that scarce resources force practitioners to compete, which inhibits their ability to cooperate effectively, leading to suboptimal use of resources and variations in care” (Frangeskou et al., 2020, p. 1180).

“Increasing demand of health care and limited resources have made it necessary to reorganize and improve health care operations in Turkey” (Camgoz-Akdag et al., 2017, p. 779).

“Worldwide, healthcare systems struggle to sustain the delivery of services at a time of increasing demand, limited resources and growing expectations from users, coupled with dealing with the aftermath of the Covid-19 pandemic and the threat of other outbreaks” (Williams & Radnor, 2022, p. 1126).

“The lack of resources results from the demands of other societal stakeholders [...]” (Wilhelm et al., 2020, p. 1189).

“[...] a more efficient and effective use of scarce resources” (Foglia et al., 2022, p. 9).

“There is a rapidly growing pressure on health care institutions to increase their efficiency and increase satisfaction of patients, physicians, nurses, staff, and stakeholders by adopting new methodologies with the same level of resources” (Camgoz-Akdag et al., 2017, p. 780).

Value cocreation

“After all, cocreation of value is at the heart of service-for-service exchange and S-D logic” (Lusch & Vargo, 2014, p. xvi).

Co-production of services

“There is a growing body of literature on co-producing healthcare services, which, to some extent, may be leading the way, particularly in mental health services [...] Co-production is featured in the literature within the context of improving healthcare systems (e.g. see Batalden et al., 2016; Filipe et al., 2017; Kaehne et al., 2018) and is seen as a model of service delivery, which should have a positive impact on service users (patients) and on the wider social system (Realpe and Wallace, 2010). Black and Gallan (2015) extend this discussion to emphasise the importance of organisations within the healthcare system (also referred to a network) to engage with one another in order to enhance patient well-being and quality of life and to co-create value with the patient/customer” (Williams & Radnor, 2022, p. 1131).

“[...] one of the most important currents of research in public administration is the concept of creating value for the customer and co-production of public services” (Ludwiczak, 2021, p. 23).

“Co-ordination of care delivery to a patient with other specialists and/or nursing staff, within a care organization (e.g. expansion of services) and/or between care organizations (e.g. primary and secondary care)” (de Bont et al., 2016, p. 11).

“ [...] understanding of the delivery process of public services is based upon co-production with service users (Osborne et al., 2015). Gronoos (2007) highlights that in the case of services, the production process is iterative and production and consumption occur concurrently” (Williams & Radnor, 2022, p. 1129).

“A benefit of co-producing patient journey mapping tools ‘from the ground up’ is that the tools inherently make sense, not only to those who developed them, but also to their colleagues” (Kelly et al., 2017, p. 540).

“A useful addition to the discussion around co-creating value comes from Black and Gallan (2015) who advocate that healthcare service networks can enhance communication and the co-creation of value. Such networks can include individuals, groups or organisations” (Williams & Radnor, 2022, p. 1130).

“The SNPs [stroke nurse practitioners] tie together different professional groups, argue for adhering to or ignoring KPIs, manage external audit (such as SNAAP), using the informal “authority” of the pathway to facilitate pathway co-ordination through negotiation of resource allocation and scheduling, coach and help professionals to build shared understanding, the specific knowledge and needs of the pathway, etc” (Frangeskou et al., 2020, p. 1178).

«The Theory of Constraints' emphasis on adopting a systems view is particularly relevant in healthcare, which often involves the co-ordination of numerous services» (Mould et al., 2010, p. 1).

“Co-ordination and integration of care is one of the identified dimensions of patient-centred care and is integral to efficient patient flow” (Murphy et al., 2019, p. 49).

“The above shows that CMs [case managers] were engaged in coordinating patient and institutional resources in space and time while also taking the diseased body and the pathway into consideration. The complexity of health care is mirrored in the cancer patient pathways, and by handling this complexity, we argue, CMs embody the capacities of the broker by coordinating the co-existing objects of care comprising cancer diagnostics” (Aarhus et al., 2019, p. 6).

“Defining characteristics of care pathways include: [...] the coordination of the care process by coordinating the roles and sequencing the activities of the multidisciplinary care team, the patients and their relatives”. (Schrijvers et al., 2012, pp. 1-2).

“Trained staff could also facilitate the coordination between all the actors: physicians, oncologists, and Radiologists” (Cherif et al., 2020, p. 9).

“[...] process orientation in hospitals can be achieved in two ways: By implementing coordination mechanisms (such as clinical pathways), horizontal processes are put on top of the existing vertical structure, without changing the functional organisation. A second manner to achieve process-oriented thinking is to consider the needs of the patient as the basis of the creation of a new organisational structure” (Gemmel et al., 2008, p. 1210).

“The care-coordinating role enables the pooling of team capacity to ensure contact is made with new patients as soon as possible. Similarly, the coordinator pulls in other professions as and when required by the patient or relatives” (Williams & Radnor, 2022, p. 1140).

Knowledge sharing

“As enterprises increasingly become part of a network of actors that work collaboratively to cocreate value, the need arises for the entire network or community of actors to be a knowledgegenerating and knowledge-using mechanism for sustainable market creation” (Lusch & Vargo, 2014, p. 66).

Knowledge-driven sector

“A collaborative network of organisations, teams and individuals is needed to develop the communication and knowledge to aid seamless transition across this network” (Williams & Radnor, 2022, p. 1130).

“To maximise effectiveness, all staff involved in a patient's care need to operate with a 'shared vision' of care regarding the likely discharge date and destination for each patient, so that investigations and interventions can be implemented sequentially to ensure that the patient receives the right care, in the right place, at the right time before discharge” (Clark et al., 2014, p. 263).

“The final proposition [of the SERVICE framework] builds on these collaborative efforts by capturing the knowledge from across the healthcare system in order to improve the service experience and to ensure improvements are sustained” (Williams & Radnor, 2022, p. 1131).

“Public service systems need to generate and capture knowledge to help deliver and sustain effective service experience” (Williams & Radnor, 2022, p. 1131).

“Edmondson et al. (2001, p. 705), in their study of cardiac surgery departments, emphasised how “group-level reflection” taking place “through formal meetings, informal conversation, and shared review of relevant data” contributed to better co-ordination of new practices in an operating room” (Frangeskou et al., 2020, p. 1181).

“The third proposition focuses on the importance of relationships within what is a knowledgedriven sector. Technology is providing a platform in which the nature of

relationships between public sector organisations, politicians and service users is changing” (Williams & Radnor, 2022, p. 1129).

“Knowledge learned in the change process needs to be efficiently distributed across the organization” (Wackers et al., 2021, p. 8).

“Integrating knowledge from team members' different functional areas increases the likelihood that the team will develop successful product, process, or market innovations” (Kuratko et al., 2001, p. 62).

Systemic interdependencies

“This results in systemic interdependencies. Society and, along with it, many institutions, such as language, norms, industries, markets, and organizations (e.g., firms, or enterprises) are created to facilitate this exchange system for efficiency and coordination purposes” (Lusch & Vargo, 2014, p. 4).

Teamwork teamwork

“The ability to act as independent units is of limited value, and there is a far greater need for negotiated relationships to include policymakers, other public service organisations, service users, citizen and other stakeholders” (Williams & Radnor, 2022, p. 1129).

“Prior research investigated the right orchestration of consultations and care delivery [7, 18–21], as well as the role of rigorous teamwork design [22, 23] as key factors to improve healthcare process and patient experience” (Cherif et al., 2020, p. 2).

“Collective entrepreneurship results in team-based endeavors in which the whole of the effort exceeds the sum of individuals' contributions” (Kuratko et al., 2001, p. 62).

“In the meantime, the key remains encouraging clinical leaders to develop skills in networking and working in partnerships” (Matthias & Brown, 2016, p. 1449).

“The challenge of developing effective teamwork in hospitals is acknowledged in the literature, as hospitals have both a hierarchical structure and independent professional groups with deep-rooted stand points on scope of practise” (Murphy et al., 2019, pp. 49-50).

“[...] there is an increasing reliance on a variety of providers for service delivery, working towards the “modern model of integrated care” [...]” (Matthias & Brown, 2016, p. 1449).

“Viewing [the care pathway] implementation as a multidependency puzzle also provides a useful contingent framework for understanding (in research and practice) the networked capacity questions that characterise most healthcare systems composed of shared and/or multitasking resources” (Frangeskou et al., 2020, p. 1194).

“Similarly, Greenhalgh (2008) showed that successful routines depended on collaborative interactions between staff members” (Frangeskou et al., 2020, p. 1181).

“Traditionally, healthcare services have recognised the need for some kind of partnership with patients” (Williams & Radnor, 2022, p. 1131).

“[...]a system of mutual interactions that will be the most beneficial for both parties” (Ludwiczak, 2021, p. 26).

Shared language

“Language helped standardize the relational statements used in communication and thus was an effective and efficient way for relationship between actors to emerge and proliferate, which led to the rise of cocreation practices and systems” (Lusch & Vargo, 2014, p.138).

Group communication

“Each society forms its own “cultural imaginaries” or societal “stories” that are shaped by the existing value system, media, political policies, religion, etc.” (Bernacki et al., 2021, p. 3).

“The experience [evolution of the pathway mapping tools] demonstrated the value of the pathway in providing: a more systemic appreciation of care activities; better communication and a shared understanding of the current organisation of care; a means of comparing practices; a tool for analysing the current system; a focus for debating changes to current practices” (Mould et al., 2010, p. 5).

“The challenge of providing a more universal language for pathway mapping has led to replacing text with symbols, chosen to relate to the target audience” (Mould et al., 2010, p. 2).

“In a healthcare setting, process maps (and other artefacts (Pentland and Feldman, 2008) like textual descriptions can help span knowledge boundaries, improve visibility and clarity of the process (i.e. roles, sequence, etc.), increase shared understanding of the distinct value added by different professions and, hence, enhance intergroup communication” (Frangeskou et al., 2020, p. 1190).

“One Aboriginal person may interact with 50 or more health professionals as they travel from home, to hospital to home, with most of these conversations occurring in English, which may be their second or third language. Access to interpreters may not be available at some sites, and they may or may not be accompanied by family members” (Kelly et al., 2017, p. 536).

“Although factors connected to communication were not addressed frequently, it is strongly related to other important themes, such as strategy, engagement and leadership” (Wackers et al., 2021, p. 8).

“Communication strategies play a large role in changing attitude and mentality of workforce” (McCracken & Edwards, 2017, p. 9).

“Communication is critical to the delivery of safe patient care” (O'Brien et al., 2015, p. 1).

From transactional to relational

“Likewise, G-D logic is focused on transactional exchange and thus enterprises have to be encouraged to take a “relational,” long-term, customer perspective” (Lusch & Vargo, 2014, p. 73).

A relational approach

“Similarly, there has been a call for public sector organisations to move beyond the short-term, transactional approach to a relational approach. This emphasises three elements: building system-wide relationships [...]” (Williams & Radnor, 2022, p. 1129).

“There is also a need to move away from short-term transactional relationships (often used within product-dominant settings) (McLaughlin et al., 2009) to develop long-term relationships across service systems (McGuire, 2012). The majority of “public goods” (whether provided by government, the non-profit and third sector or the private sector) are, in fact, not “public products” but rather “public services” that are integrated into people’s lives“ (Williams & Radnor, 2022, p. 1130).

“[...] the development of long-term relationships across the service system rather than seeking short-term transactional value” (Williams & Radnor, 2022, p. 1137).

“Over time the term has been adopted to reflect the increasingly service-dominant nature of most economies, shifting focus from manufacture of goods to the provision of services” (Matthias & Brown, 2016, p. 1438).

“Healthcare providers need to pay particular attention to the relational and informational dimensions of the experience according to the stage of the healthcare process and patients’ profiles” (Cherif et al., 2020, p. 10).

“This [attending to patient needs] also includes planning for future care needs and long-term goal achievement outside the inpatient setting” (Rolls et al., 2020, p. 1).

“Previous research has revealed a range of themes that SDS [service delivery system] should emphasise: relational quality reflects how patients perceive their interactions with staff members [...]” (Ponsignon et al., 2018, p. 2332).

“The establishment of effective telehealth is particularly difficult when there is no established patient- HCP [healthcare professionals] relationship or when that relationship is weak or strained” (Bernacki et al., 2021, p. 5).

“In recent years, repeated calls have been made to include materiality and relational practice in theory” (Torseth & Adnanes, 2022, p. 3).

“This [stakeholder evaluation matrix] can be used to identify those who are most important to the success of a streamlined pathway, but who are least engaged, and core frontline health care staff leading the project can then focus efforts on building relationships with these individuals” (Rizan et al., 2020, p. 207).

Active beneficiary

“[...] we need to understand this huge segment of society not as passive aid recipients and consumers (Goods Dominant Logic), but as innovative entrepreneurs constantly co-creating solutions to survive in their daily life (Service-Dominant Logic)” (Lusch & Vargo, 2014, p. 0).

Patient involvement

“Patients no longer interact with the healthcare team as passive recipients of services. They get involved in collaborative interactions fragment all along the care process to improve their healthcare experience, especially for chronic diseases such as cancer” (Cherif et al., 2020, p. 2).

“Traditional care delivery with one specialist within a care organization responsible for the care delivery to a patient, supported by general nursing, technical and/or administrative staff” (de Bont et al., 2016, p. 11).

“Patient unaware of clinic process [...] Patients can sometimes spend unnecessary time in the waiting room, unsure of where to go next” (McDermott et al., 2013, p. 6).

«A second step to complete the study of experiences and pathways requires a different data collection methodology for patients who completely defer to the decisions of the medical team and allow themselves to be guided through the medical process only” (Cherif et al., 2020, p. 9).

“In addition, cancer patients are particularly involved in their healthcare experience as the healthcare process is still complex and poorly coordinated” (Cherif et al., 2020, p. 2).

“Finally, patient engagement in the design of many improvement initiatives has been lacking, missing an opportunity to increase service value” (Wackers et al., 2021, p. 7).

“The care pathway’s overall goal of improved quality within the mental health services e.g., increased user participation” (Torseth & Adnanes, 2022, p. 5).

Generic actors

«Particularly important is the move in S-D logic to generic actors versus producers and consumers and toward systems and network perspectives” (Lusch & Vargo, 2014, p. 27).

Multi-professional roles

“Generic roles, conversely, have a broader scope and cover a larger part of the care pathway. Generic roles focus on the organisation of care and treatment, often integrating care and cure activities.” (de Bont et al., 2016, p. 11).

“The multi-professional roles of the team enable them to provide an integrated service which includes outreaching and collaborating with a spectrum of health and social care services” (Williams & Radnor, 2022, p. 1136).

“Some new professionals - such as advanced nurse practitioners, physician associates and specialised nurses - incorporate a generic perspective into their work, considering and responding to the wider organisational aspects of patient treatment” (de Bont et al., 2016, p. 10).

“There were no formalised roles or project champions within the team [Diabetes Day Centre staff]” (McDermott et al., 2013, p. 682).

“[...] benefits of role diversification facilitating care from ‘the right person at the right time’ and enhanced team working and communication [...]enhanced teamwork and role redistribution were central to this project’s achievements” (Murphy et al., 2019, p. 50).

“The flexibility of the team is a key attribute as one staff interviewee noted, “we go wherever the patient is, this can be their home, nursing home, day care unit or hospital”. The span of communication extends across organisational and professional boundaries, but interestingly this is not dependent on technological solutions” (Williams & Radnor, 2022,

p. 1136) .

“The HD [Huntington’s disease] team operate beyond the boundaries of their professional roles and collectively provide information and assistance that help their patients remain independent for as long as possible and to make the transition across the various agents within the healthcare and social care system/network as seamless and well integrated as possible [...]The weekly HD [Huntington’s disease] team meeting is also integral to enabling this system/network approach to be managed and sustained. Collectively, the team is able to draw on their shared experiences and knowledge to ensure signposting is up-to-date and accurate” (Williams & Radnor, 2022, p. 1136).

“The wider integration across the healthcare and social care system (network) probably requires further examination. It is evident that members of the team are acting as “brokers or boundary spanners” (Long et al.,2013) to bridge organisational boundaries and ensure consistency of service delivery” (Williams & Radnor, 2022, p. 1137).

“[...] the need for more generic or organising competences in an increasingly complex medical field which offers more treatment on an out-patient basis” (de Bont et al., 2016, p. 10).

“Brokers [case managers] have thus been described as being able to bridge cultural divides in ethnically heterogenic care settings (Jezewski, 1990) or to organise and legitimise care through therapy management groups” (Aarhus et al., 2019, p. 3).

Specialized skills and knowledge

“Humans specialize and exchange because they have limited but often advantageous individual abilities” (Lusch & Vargo, 2014, p. 4).

Medical specialists

“Specialisation enables professionals to extend their role and to carry out clinical tasks relatively independently from physicians as they develop expertise and clinical routines in a particular clinical area” (de Bont et al., 2016, p. 8).

“Medical professionals are typically categorised as specialists performing specialist tasks, but our observations confirm that they are also involved in a range of quite mundane and generalist tasks – including a great deal of basic simultaneous and asynchronous “changeovers” (Frangeskou et al., 2020, p. 1190).

“Patient care is delivered through a collection of professional specialists who operate in distinct, hierarchical arrangements across organisational units” (McCracken & Edwards, 2017, p. 2).

“The further evolution of the hospital structure has been characterised by increasing specialisation (within the functions) and centralisation (to capture economies of scales)” (Gemmel et al., 2008, p. 1209).

“[...] new technologies facilitate the development of specialised roles”(de Bont et al., 2016, p. 10).

“Increased specialisation and standardisation of services, efficiency requirements and growing medical and technological improvements reflect how contemporary healthcare systems are organised” (Aarhus et al., 2019, p. 1).

“[...] we engaged with a multidisciplinary specialist team, which was developed to deliver services within the community for patients diagnosed with Huntington’s disease (HD)” (Williams & Radnor, 2022, p. 1133).

APPENDIX B: IN-DEPTH INTERVIEW INFORMATION SHEET (ENGLISH)



Research project about patient pathways

Do you want to participate in the research project "Pathway"?

We would like to invite you to participate in a research project about patient pathways. This term includes the patient's encounters and experiences with different parts of the health care during a period of illness. In this information sheet, we provide you with information about the project and what participation will involve.

What is the project's purpose?

The main goal of the Pathway research project is to develop models and methods that simplify arriving at a common understanding and communication across different disciplines and professionals in health care, but also to communicate directly with patients and their next-of-kin. The project is divided into packages and consists of sub-studies. In this study, we focus on health care workers' experiences with patient care processes. The study is not limited to a specific diagnosis. Questions we ask in the study are:

- What kind of information should be included in a patient pathway?
- How can information in a patient pathway be communicated across service providers?
- How can the patient be involved in their own patient pathway?
- How to handle variation within the patient pathway?

The results of the study are disseminated through verbal and written scientific and popular science publications.

Who is responsible for the research project?

SINTEF Digital, the University of Oslo, and NTNU are responsible for the project. The project manager is Senior Research Scientist, Ragnhild Halvorsrud, at SINTEF. The study is conducted in collaboration with the University of Aalto, Finland. The project will run from 1/8-2021 to 31/12-2025, and the project receives financial support from the Research Council of Norway.

Why are you asked to participate?

You are asked to participate because you are employed in municipal or specialist health care, and either have patient contact, or you work with the development of digital solutions to produce patient pathways/ treatment plans.

What participation in the project involves?

Participation involves completing an individual interview. We conduct the interview digitally or face to face, based on what is most convenient for you. The length of the interview is a maximum of one hour. Audio recordings (if you may allow us to do so) and notes from the interview will be made.

Do I have to take part?

It is entirely voluntary to participate in the study. If you wish to participate, sign the consent form on the last page. You can withdraw your consent at any time without giving any reason. All your personal information will then be deleted. It will not have any negative consequences for you if you do not want to participate or later choose to withdraw.

Will my taking part in this project be kept confidential?

We will only use your information for the purposes described in this information sheet. Only the project group in SINTEF, the University of Oslo, and a master's student from the Inland Norway University of Applied Sciences have access to information. We treat the information confidentially and in compliance with the privacy protection regulations. SINTEF will be responsible for data management and processing of personal data in this study. The data material will be stored on encrypted and authorized computers and cloud services. As an extra layer of protection, your name and contact information will be stored separately from the rest of the data material. All data will be anonymized before use in the project's publications and presentations. It will not be possible to trace anything back to you as a person.

What happens to your information when we finish the research project?

The information about you will be anonymized when the project is finished, and no later than the end of 2025. Name lists, scrambling keys, and audio recordings will be deleted at the same time.

What rights do I have as a participant?

As long as you can be identified in the data material, you have the right to:

- access to which personal information is registered about you, and to receive a copy of the information,
- to have personal information about you corrected,
- to have personal information about you deleted, and
- to send a complaint to the Norwegian Data Protection Authority about the processing of your personal data.

What allows us to process personal information about you?

We process information about you based on your consent. On behalf of SINTEF, UiO, and NTNU, NSD - the Norwegian Center for Research Data AS has assessed that the processing of personal data in this project is in accordance with the privacy regulations.

What are the possible disadvantages of taking part?

Besides the use of time, there are no disadvantages to participating.

Where can I find out more?

If you have questions about the study or concerning your rights, please contact:

- SINTEF at project manager, Ragnhild Halvorsrud, e-mail: ragnhild.halvorsrud@sintef.no, telephone: +47 977 38 883
- SINTEF's privacy coordinator, Jan Wåge, e-mail: jan.wage@sintef.no, telephone: +47 405 56 650
- If you have questions related to NSD's assessment of the project, you can contact: NSD - Norwegian Center for Research Data AS by e-mail: personvertjenester@nsd.no, telephone: +47 555 82 117

Best regards,

Ragnhild Halvorsrud
Project manager/ senior researcher

Consent Statement

I have received and understood information about the Pathway project, and have had the opportunity to ask questions. I freely agree to participate in the interview.

I agree that my information will be processed until the project is completed.

(Signature by project participant, date)

APPENDIX C: IN-DEPTH INTERVIEW INFORMATION SHEET (NORWEGIAN)



Forskningsprosjekt om pasientforløp

Vil du delta i forskningsprosjektet "Pathway"?

Dette er et spørsmål til deg om å delta i et forskningsprosjekt som handler om *pasientforløp*. Dette begrepet omfatter pasientens mange møter, opplevelser og erfaringer med ulike deler av helsevesenet gjennom en sykdomsperiode. I dette skrevet gir vi deg informasjon om prosjektet og hva deltakelse vil innebære for deg.

Formål

Forskningsprosjektet Pathway har som hovedmål å utvikle metoder og digitale visuelle verktøy som skal gjøre det lettere å forstå og samarbeide om et pasientforløp på tvers av fag og roller i helsetjenesten, men også for å kommunisere direkte med pasienter og deres pårørende. Prosjektet består av flere delstudier. I denne studien fokuserer vi på ansatte i helsetjenestenes erfaringer med pasientforløp. Studien er ikke avgrenset til spesifikke diagnoser. Spørsmål vi stiller i studien er:

- Hva slags informasjon bør inngå i et pasientforløp?
- Hvordan kan informasjon i et pasientforløp kommuniseres på tvers av tjenesteutøvere?
- Hvordan kan pasienten involveres i sitt eget forløp?
- Hvordan skal man håndtere variasjonen i pasientforløp?

Resultatene fra studien bli formidlet gjennom muntlige og skriftlige vitenskapelige og populærvitenskapelige publikasjoner.

Hvem er ansvarlig for forskningsprosjektet?

SINTEF Digital, Universitetet i Oslo og NTNU er ansvarlige for prosjektet. Prosjektleder er seniorforsker Ragnhild Halvorsrud ved SINTEF. Studien gjennomføres i samarbeid med Universitetet i Aalto, Finland. Prosjektet varer fra 1/8-2021 til 31/12-2025, og prosjektet mottar finansiell støtte fra Norges Forskningsråd.

Hvorfor får du spørsmål om å delta?

Du får spørsmål om å delta fordi du er ansatt i et helseforetak eller i kommunal helse- og omsorgstjeneste og enten har pasientkontakt, eller du jobber med utvikling av digitale løsninger for å framstille pasientforløp/behandlingsplaner.

Hva innebærer deltakelse i prosjektet for deg?

Deltakelse innebærer å delta i et individuelt intervju. Vi gjør intervjuet digitalt eller ansikt til ansikt, ut fra hva som passer best for deg. Intervjuet tar maksimalt 1 time. Vi gjør lydopptak og notater fra intervjuet.

Det er frivillig å delta

Det er frivillig å delta i studien. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst trekke ditt samtykke tilbake uten å oppgi noen grunn. Alle dine personopplysninger vil da bli slettet. Det vil ikke ha noen negative konsekvenser for deg hvis du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger

Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrevet. Det er kun prosjektgruppen i SINTEF, Universitetet i Oslo og en masterstudent fra Høgskolen i Innlandet som har

tilgang til dine opplysninger. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket. SINTEF vil være behandlingsansvarlig for personopplysninger og datamateriale i denne studien. Datamaterialet vil bli oppbevart på krypterte og godkjente datamaskiner og skytjenester. Som en ekstra beskyttelse vil ditt navn og kontaktinformasjon oppbevares separat fra resten av datamaterialet. Alle data vil bli anonymisert før bruk i prosjektets publikasjoner og presentasjoner. Det vil ikke være mulig å spore noe tilbake til deg som person.

Hva skjer med opplysningene dine når vi avslutter forskningsprosjektet?

Opplysningene om deg anonymiseres når prosjektet avsluttes, og senest innen utgangen av 2025. Navnelister, koblingsnøkler og lydopptak vil samtidig bli slettet.

Dine rettigheter

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg, og å få utlevert en kopi av opplysningene,
- å få korrigert personopplysninger om deg,
- å få slettet personopplysninger om deg, og
- å sende klage til Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?

Vi behandler opplysninger om deg basert på ditt samtykke. På oppdrag fra SINTEF, UiO og NTNU har NSD – Norsk senter for forskningsdata AS vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Mulige ulemper

Utover tidsbruken er det ikke noen ulemper ved å delta.

Hvor kan jeg finne ut mer?

Hvis du har spørsmål til studien, eller ønsker å benytte deg av dine rettigheter, ta kontakt med:

- SINTEF ved prosjektleder Ragnhild Halvorsrud, ragnhild.halvorsrud@sintef.no, telefon: 977 38 883.
- SINTEFs personvernkoordinator Jan Wåge, e-post: jan.wage@sintef.no, telefon: 405 56 650
- Hvis du har spørsmål knyttet til NSD sin vurdering av prosjektet, kan du ta kontakt med: NSD – Norsk senter for forskningsdata AS på e-post: personverntjenester@nsd.no, telefon: 55 58 21 17.

Med vennlig hilsen

Ragnhild Halvorsrud
Prosjektleder/seniorforsker

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet Pathway, og har fått anledning til å stille spørsmål. Jeg samtykker til å delta på intervju.

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet

(Signert av prosjektdeltaker, dato)

APPENDIX D: IN-DEPTH INTERVIEW GUIDE (ENGLISH)

In-depth Interview Guide

Introduction

Thank you for agreeing to participate and we believe your contribution to this study will benefit you and similar institutions in improving patient care processes.

The aim of this project is to develop a modelling language and toolkit for a common understanding and management of complex patient pathways.

In this interview, we are interested to learn your experiences and perceptions about the patient pathway in general. The Norwegian equivalent to the term "patient pathway" is "pasientforløp". We will raise questions to guide the discussion, but feel free to explain in-depth and beyond the questions we pose.

Review information sheet and consent form; particular focus on voluntary participation, storage and access to data, and information about audio recording.

Do you have any questions before we begin?

Start audio recording and proceed.

Topic	Main question	Probing questions	Short notes of responses
Background	Could you tell us about your position and your main responsibilities?	How long have you served in this position?	
		What are your main responsibilities in this position?	
		Therefore, the main responsibility is (tick on the text box in front of the choices)	Clinical <input type="checkbox"/> Technical <input type="checkbox"/> Administrative/Coordination <input type="checkbox"/> Other _____
Understanding the concept of 'patient pathways', aka. pasientforløp	'Patient pathway' (commonly known as pasientforløp in Norway) can mean and contain different things to different individuals.	How is it used in your department/unit/care system? Is there an agreed definition of the term?	

	How do you explain the concept of patient pathway/ pasientforløp in your context?	If yes, what is the definition? can you explain the essence of the definition?	
		Does the term pasientforløp hold a similar meaning among staff in your department/unit/ care system?	
		What are the characteristics of a patient pathway the majority understand in common?	
		If we look beyond your organization and more generally in the health service, do you find that there are several different understandings of the concept of patient pathways/pasientforløp?	
Some institutions/departments/units have a written document of pasientforløp that is used as a tool to be shared amongst. Do you have any such tools? What does your pasientforløp look like?		What does it include? (*time points, appointments, medications, treatments)?	Proceed if the respondents' institution doesn't have such kind of tool
		Who/which agencies (*roles as specialist, GP, NAV ++)	
		How is it presented? (*text, table, chart, other visual representation)	
		How is it made? Or developed?	
		Who was involved in its creation?	
		What is its scope? Does it include all the services your institution/department/unit provides? (Diagnosis, treatment, and/or rehabilitation)	
		What is its scope in terms of including the services your patient might need beyond your institution/department/unit?	

Understanding the structured 'Patient pathway'	In some units/departments/facilities, there is a structured 'patient pathways' such as the so-called <i>behandlingsforløp, pakkeforløp, gode pasientforløp, helhetlige pasientforløp</i>) concept in organizing the care provision. Others may not have used such terminologies.	If you have understood what these terms mean, are they different from pasientforløp?	
		How different are they?	
		If you do not know the details, have you heard of the terms?	
		If you heard of the terms, from who? When? How?	
	Would you tell us the experiences of your unit/department? For that matter, any type of standardized care that you are familiar with?	In the unit/department/facility/task you coordinate, do you currently use a structured/standardized patient pathway? (aka .pakkeforløp, gode pasientforløp, helhetlige pasientforløp)	
		If you are not currently using it, have you ever used it? If not, why not?	
		If you know about it but are not using it, why not?	
	Standardization of patient pathway (pasientforløp)	Do you think standardizing a patient pathway is beneficial? Could you elaborate on that?	
Can all patient pathways be standardized? Feel free to give examples			
What is the challenge of standardizing patient pathways?			
Let us come back to our patient pathway/pasientforløp discussion that we started at the beginning. In the following section, we will be asking questions about how your pasientforløp, or patient care processes, in general, are organized. For example, in terms of the scientific evidence the care process is based on; who is involved in designing, using, monitoring, and communicating the care process, and the participation of patients and family/next-of-kin in the process, etc.			
Organization and Coordination of care process/ patient pathways/ pasientforløp	Could you explain how the coordination of patient pathways at your institution is?	(Besides treatment guidelines) do you have any document of the patient pathway/pasientforløp that you work with? Could you elaborate on the details?	
		If there is no document guiding the patient pathway, how are the patient	

		pathways (in terms of diagnosis and treatment) built?	
		If there is no structured patient pathway/pasientforløp, that means the decision is left to each clinician to establish a patient pathway/pasientforløp for each patient?	
		If any, do you believe that the content of your care is updated based on the most current scientific evidence?	
		What methods do you employ to keep the evidence up to date?	
		How does the coordination of activities look like?	
		Are there time stamps?	
		If so, how optimum (do you think) is the timing of activities within the care process/pasientforløp?	
		Do you work in interdisciplinary teams where there is a need for a common understanding of patient pathways across professional competence, e.g., clinical, technical and administrative?	
		How do you manage disagreements, misunderstandings, or ambiguities?	
	Let us discuss how the coordination of patient care is communicated among clinical and non-clinical staff.	How is it communicated to the staff? (Poster, a booklet, electronic tool, integrated into the EMR)	
		How familiar (do you think) are the team members with the various steps in the care process/pasientforløp?	

	How is the communication culture regarding patientforløp?	How well do you think the team members are engaged in the organization of the care process? Is there any room for improvement in engaging the staff? If there are ways of getting feedback from the staff, how is it arranged?	
Patient-centeredness	How do you see your institution regarding the provision of patient-centered care? Meaning "Providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions." The Institute of Medicine	Does your institution have a patient-centered vision? In what way does it manifest itself?	
		How well are the care processes organized by taking the holistic nature of a patient? i.e., considering a patient beyond the sickness	
		Do you believe the organizational structure is designed to accommodate the needs and wills of a patient?	
		Are there ways of monitoring the patient-centeredness of your patient pathway? What would you like to improve? How?	
Communication with patients and family	How is the engagement of care providers and patients/family throughout the care process?	How and when do you communicate with the patient throughout the care process? Is there enough time (allocated) for patient communication?	
		Is the patient pathway (patientforløp) communicated directly to the patient? If yes, is the description shown to the patient like the description used internally?	

		Are the patients or family provided with candid (frank, open, straightforward) information regarding their health? Are patients explicitly asked for consent to the proposed next step in a care process? What are the common means of patient communications? Do you have ways of measuring patient feedback? How well do you think the patients are engaged? Do they need empowerment to take part in the decision of their care process?	
Collaboration across other health and social service institutions	Patient pathways can transcend through various service providers and institutions. Do you think that there is collaboration How and when do you communicate with the patient throughout the care process? (Such as GP offices, Emergency health institutions, rehabilitation centers, home care, social service) How well do you think your institution's patient pathway is designed in collaboration with other service outlets?	Who initiates and maintains such collaboration and coordination?	
		How does your institution communicate information among the different care provision outlets?	
		There is a claim that patients often play a messenger role between institutions. How do you respond to that?	
		How seriously taken is communication between other institutions?	
		How do you ensure the care process is collaborated across the various service outlets for your patients?	
		If there is collaboration and coordination:	

		Do you have ways of monitoring? Do you think there are areas where collaboration and coordination of patient pathway should be strengthened? Could you elaborate on how?	
	If there is no collaboration and coordination	What do you think are the reasons for its absence? How do you think collaboration and coordination in patient pathways development and implementation can be improved?	
Monitoring and follow up of the care process	How do you ensure that the care process is following the established standards of care?	Do you have a routine monitoring system? Indicators? Do you explicitly specify the goals of your care process to individual patients? How variable could the care process be between patients? How much is the monitoring of the care processes based on the feedback from patients and their families? Are there any regular ways of improving the care process at your institution? Explain how your approach looks like?	
Digital technology	Does your institution use any digital technology to manage the patient pathway?	How does it affect the care process? How interoperable is your system with other institutions you send/receive patients? In what way would you like it to be improved?	
Legislation and external environment	How supportive are legislations and governance systems to create a patient pathway?	Does your institution have enough mandate to create a patient pathway? How about creating in collaboration with other stakeholders?	

		Can you initiate and create a patient pathway at your institution level or is it a top-down approach?	
Anticipated improvement areas	Do you see a need for a common approach to describing patient pathways - consisting of definitions, visualizations, various diagrams and examples?		
	How would you like to improve, or make your patient flow even better?	If you need to improve it, what are the areas you would prioritize? In terms of ... Ways of visualizing? Extending and cooperating with other institutions and service delivery points? Use of digital technologies? Integration into the EMR? Access to the patients? Better monitoring and evaluation indicators? Ways of updating?	
For IT personnel	Is there any model and IT structure that was made to implement patient pathways?	What modelling language do you use to model the patient pathway in your institution? Could you discuss the advantages and limitations of your model and modeling language?	
Conclusion	Is there anything additional you want to add into? Any questions or comments, please?		

Thank you so much for your time and for responding to our questions!

APPENDIX E: IN-DEPTH INTERVIEW GUIDE (NORWEGIAN)

Intervjuguide for dybdeintervju

Introduksjon

Takk for at din deltakelse. Ditt bidrag vil være til nytte for din egen og andre institusjoner i å forbedre pasientbehandlingsforløp.

Målsetningen med dette prosjektet er å utvikle et modelleringspråk og verktøykasse for en felles forståelse og håndtering av komplekse pasientforløp.

I dette intervjuet er vi interessert i å lære om dine erfaringer og oppfatninger om pasientforløp på generell basis. Med «pasientforløp», så mener vi både prosesser som er svært strukturerte og standardiserte, og de som ikke er det. Det er flere andre terminologier som brukes, som *behandlingsforløp*, *pakkeforløp*, *gode pasientforløp* og *helhetlige pasientforløp*, som gjør det vanskelig å skille begrepene fra hverandre, eller for å fullt ut forstå betydningen av dem. Vi vil stille spørsmål for å veilede diskusjonen, men gå gjerne i dybden av og utover spørsmålene som vi stiller.

Gjennomgå informasjonsark og samtykkeskjema; særlig med fokus på frivillig deltakelse, lagring og tilgang til persondata, og informasjon om lydopptak.

Har du noen spørsmål før vi begynner?

Start lydopptak og fortsett.

Tema	Hovedspørsmål	Oppfølgingsspørsmål	Korte merknader
Bakgrunn	Kan du fortelle oss om din stilling og dine hovedoppgaver?	Hvor lenge har du hatt denne stillingen? Hva er dine hovedoppgaver i denne stillingen?	
		Derfor, er hovedansvaret (kryss av riktig alternativ i boksen)	Klinisk <input type="checkbox"/> Teknisk <input type="checkbox"/> Administrativ/ koordinerende <input type="checkbox"/> Annet <input type="checkbox"/>
Forståelse av konseptet «pasientforløp»	«Pasientforløp» kan ha ulik betydning og meningsinnhold for ulike individer.	Hvordan brukes begrepet i din avdeling/ virksomhetsenhet/ helseforetak?	

	Hvordan forklarer du begrepet, pasientforløp, i din kontekst?	Er det enighet om definisjonen av begrepet? Hvis ja, hva er definisjonen?	
		Har begrepet, pasientforløp, en lignende mening blant ansatte i din avdeling/ enhet/ helseforetak? Hvilke karakteristika ved pasientforløp er det enighet om blant flertallet?	
		Dersom vi ser utover din organisasjon og mer generelt i helsesektoren, tror du at det er ulike forståelser av begrepet pasientforløp?	
	Noen institusjoner/ avdelinger/ enheter har et skriftlig dokument om pasientforløp på deling som brukes som et verktøy. Har dere noen slike verktøy?	Hva inkluderer det? (*tidspunkter, avtaler, medisiner, behandlinger)?	
	Hvordan ser pasientforløpet deres ut?	Hvem/hvilke instanser (*roller som spesialist, fastlege, NAV ++) Hvordan presenteres det? (*tekst, tabell, diagram, annen visuell representasjon)?	
		Hvordan er det laget? Eller utviklet?	
		Hvem var involvert i opprettelsen av det?	
		Hva er omfanget? Inkluderer den alle helsetjenestene som din institusjon/ avdeling/ enhet tilbyr? (Diagnose, behandling og/eller rehabilitering)	
		Hva er omfanget når det gjelder å inkludere helsetjenester din pasient kan trenge utover din institusjon/ avdeling/ enhet?	
Forståelsen av strukturerte «pasientforløp»	I enkelte enheter/ avdelinger/ institusjoner er det strukturerte «pasientforløp», såkalte	Dersom du har forstått hva disse begrepene betyr, er de forskjellige fra pasientforløp?	

<p><i>behandlingsforløp, pakkeforløp, gode pasientforløp, helhetlige pasientforløp konsept</i> i organiseringen av helsetilbudet. Andre bruker kanskje ikke slike terminologier.</p> <p>Vil du fortelle oss om erfaringer i din enhet/avdeling?</p> <p>For den saks skyld, hvilken som helst annen type av standardisert helseomsorg som du er kjent med?</p> <p>Standardiseringen av pasientforløp</p>		Hvor forskjellige er de?	
		Hvis du ikke kjenner til detaljene, har du hørt om vilkårene?	
		Hvis du har hørt om vilkårene, fra hvem? Når? Hvordan?	
		I enheten/ avdelingen/ institusjonen/ oppgaven som du koordinerer, bruker du i dag et strukturert/ standardisert pasientforløp? (aka. pakkeforløp, gode pasientforløp, helhetlige pasientforløp)	
		Hvis du ikke bruker det for øyeblikket, har du noen gang brukt det? Hvis nei, hvorfor ikke?	
		Hvis du vet om det, men ikke bruker det, hvorfor ikke?	
		Tror du at standardiseringen av pasientforløp er fordelaktig? Kan du utdype?	
		Kan alle pasientforløp standardiseres? Kom gjerne med eksempler. Hva er utfordringen med å standardisere pasientforløp?	
<p>La oss komme tilbake til pasientforløp-diskusjonen som vi startet på i begynnelsen. I den neste delen vil vi stille spørsmål om hvordan ditt pasientforløp, eller pasientbehandlingsforløp generelt, er organisert. Når det for eksempel gjelder de vitenskapelige bevisene i behandlingsforløp, så er de basert på, hvem som er involvert i å designe, bruke, overvåke og kommunisere behandlingsforløp, og deltakelse av pasienter og familie/pårørende i prosessen mv.</p>			
Organisering og koordinering av behandlingsforløp/ pasientforløp.	Kan du forklare hvordan koordineringen av pasientforløp ved din institusjon er?	(Foruten behandlingsretningslinjer) har du noe dokumentasjon på pasientforløp som du arbeider med? Kan du utdype detaljene rundt det?	
		Hvis det ikke er noe dokument som veileder pasientforløp, hvordan er pasientforløp (med tanke på diagnose og behandling) bygget opp?	

		Hvis det ikke er noe strukturert pasientforløp, betyr det at beslutningen er overlatt til hver enkelt behandler for å etablere et pasientforløp til hver enkelt pasient?	
		Om noe, tror du at innholdet i helseomsorgen din er oppdatert basert på de nyeste vitenskapelige bevisene?	
		Hvilke metoder bruker du for å holde bevisene oppdatert?	
		Hvordan ser koordineringen av aktiviteter ut?	
		Finnes det tidsstempler?	
		Hvis ja, hvor optimalt (tror du) at registrering av tidspunkter for aktiviteter innenfor behandlingsforløpet/ pasientforløp er?	
		Jobber du i tverrfaglige team hvor det er behov for en felles forståelse av pasientforløp på tvers av faglig kompetanse, for eksempel klinisk, teknisk og administrativ?	
		Hvordan håndterer du uenigheter, misforståelser eller uklarheter?	
	La oss diskutere hvordan koordineringen av pasientomsorgen kommuniseres blant klinisk og ikke-klinisk personale.	Hvordan formidles det til personalet? (Plakat, hefte, elektronisk verktøy, integrert i elektronisk pasientjournal)	
	Hvordan er kommunikasjonskulturen rundt pasientforløp?	Hvor kjent tror du at dine teammedlemmer er med de ulike trinnene i behandlingsforløpet/ pasientforløp.	
		Hvor godt tror du at dine teammedlemmer er engasjert i organiseringen av behandlingsforløpet.	

		Er det rom for forbedring i å engasjere de ansatte?	
		Hvis det finnes måter å få tilbakemeldinger fra personalet på, hvordan foregår det?	
Pasientsentrert	Hvordan ser du på din institusjon når det gjelder forsørging av pasientsentrert helseomsorg?	Har din institusjon en pasientsentrert visjon? På hvilken måte manifesterer det seg?	
	Betydning «Å tilby helseomsorg som respekterer og svarer på individuelle pasientpreferanser, behov og verdier, og sikrer at pasientverdier styrer alle kliniske beslutninger.» Institutt for medisin.	Hvor bra er behandlingsforløpet organisert for å ta vare pasientens helhetlige karakter i betraktning? Dvs. å vurdere en pasient utover sykdommen.	
		Tror du at organisasjonsstrukturen er uformet for å imøtekomme behovene og viljen til en pasient?	
		Finnes det måter å overvåke pasientsentrertheten til dine pasientforløp på?	
		Hva vil du forbedre? Hvordan?	
Kommunikasjon med pasienter og familie	Hvordan er deltakelsen til behandlere og pasienter/familie gjennom behandlingsforløpet?	Hvordan og når kommuniserer du med pasienten gjennom hele behandlingsforløpet?	
		Er det nok tid (avsatt) til pasientkommunikasjon?	
		Kommuniseres pasientforløpet direkte til pasienten?	
		Hvis ja, er beskrivelsen som vises til pasienten lik beskrivelsen som brukes internt?	
		Får pasientene eller familien oppriktig (ærlig, åpen, rett frem) informasjon om deres helse?	

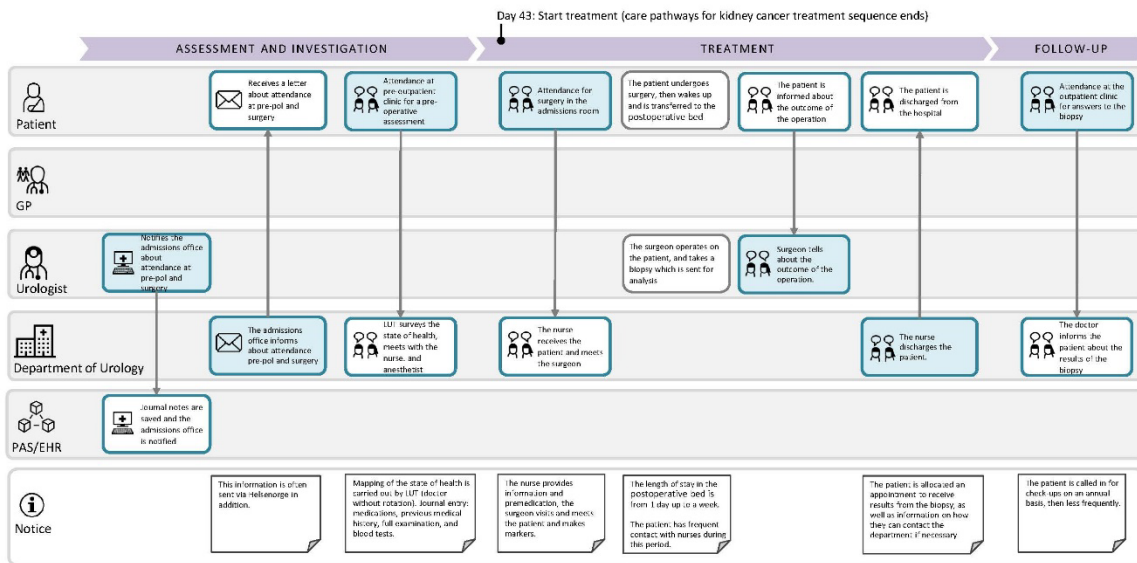
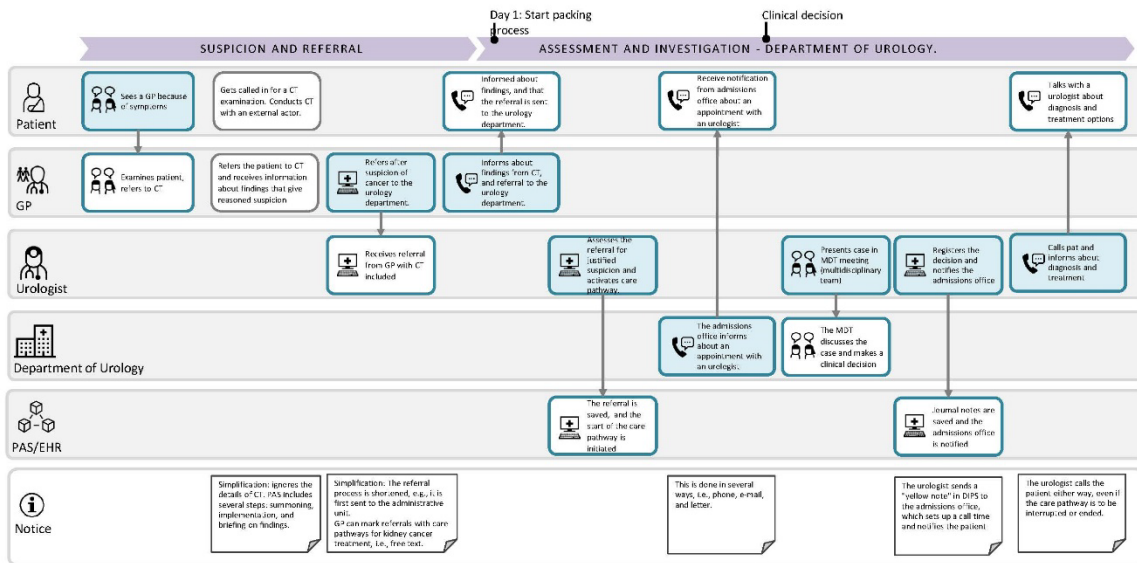
		Spørres pasienter eksplisitt om samtykke til det foreslåtte neste trinnet i et behandlingsforløp?	
		Hva er de vanlige midlene for pasientkommunikasjon?	
		Har du måter å måle tilbakemeldinger fra pasienter på?	
		Hvor godt tror du pasientene er engasjert? Trenger de økt myndiggjørelse for å ta del i avgjørelsen av behandlingsforløp deres?	
Samarbeid på tvers av andre helse- og sosialinstitusjoner	Pasientforløp kan passere gjennom ulike tjenestetilbydere og institusjoner. Synes du at det er samarbeid? Hvordan og når kommuniserer du med pasienten gjennom behandlingsforløpet?		
	(Slik som fastlegekontorer, akutte helseinstitusjoner, rehabiliteringssentre, hjemmetjenesten, sosiale velferdstjenester) Hvor godt tror du at din institusjon sitt pasientforløp er utformet i samarbeid med andre tjenestetilbydere?		
	Hvis det er samarbeid og koordinering:	Hvem initierer og opprettholder slikt samarbeid og koordinering?	
		Hvordan kommuniserer din institusjon informasjon mellom de ulike helsejensene?	
		Det hevdes at pasienter ofte spiller en budbringerrolle mellom institusjoner. Hvordan svarer du på det?	
		Hvor alvorlig tas kommunikasjon mellom andre institusjoner?	
		Hvordan sikrer du at behandlingsforløpet samarbeides om på tvers av de ulike helsejensene for dine pasienter?	

		Har du måter å overvåke på? Synes du det er områder hvor samarbeid og koordinering av pasientforløp bør styrkes? Kan du utdype hvordan?	
	Hvis det ikke er samarbeid og koordinering:	Hva tror du er årsakene til fraværet? Hvordan tror du samarbeid og koordinering i utvikling og implementering av pasientforløp kan forbedres?	
Overvåking og oppfølging av behandlingsforløpet	Hvordan sikrer du at behandlingsforløpet følger de etablerte behandlingsstandardene?	Har du et rutinemessig overvåkingssystem? Indikatorer? Spesifiserer du eksplisitt målene for behandlingsforløpet ditt til individuelle pasienter? Hvor varierende kan behandlingsforløpet være mellom pasienter? Hvor mye av overvåkingen av behandlingsforløpet er basert på tilbakemeldinger fra pasienter og deres familier? Finnes det noen vanlige måter å forbedre behandlingsforløpet på ved din institusjon på? Forklar hvordan tilnærmingen din ser ut.	
Digital teknologi	Bruker din institusjon digital teknologi for å administrere pasientforløpet?	Hvordan påvirker det behandlingsforløpet? Hvor interoperabelt er systemet ditt med hensyn til andre institusjoner du sender/mottar pasienter fra? På hvilken måte vil du at det skal forbedres?	
Lowverk og eksternt miljø	Hvor støttende er lover og styringssystemer for å skape et pasientforløp?	Har institusjonen din nok mandat til å opprette et pasientforløp?	

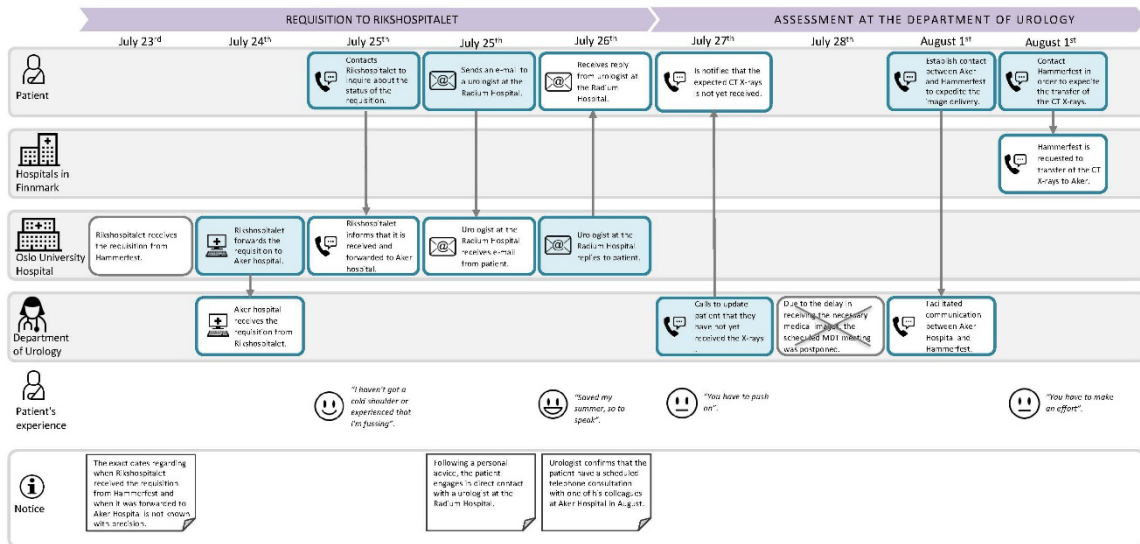
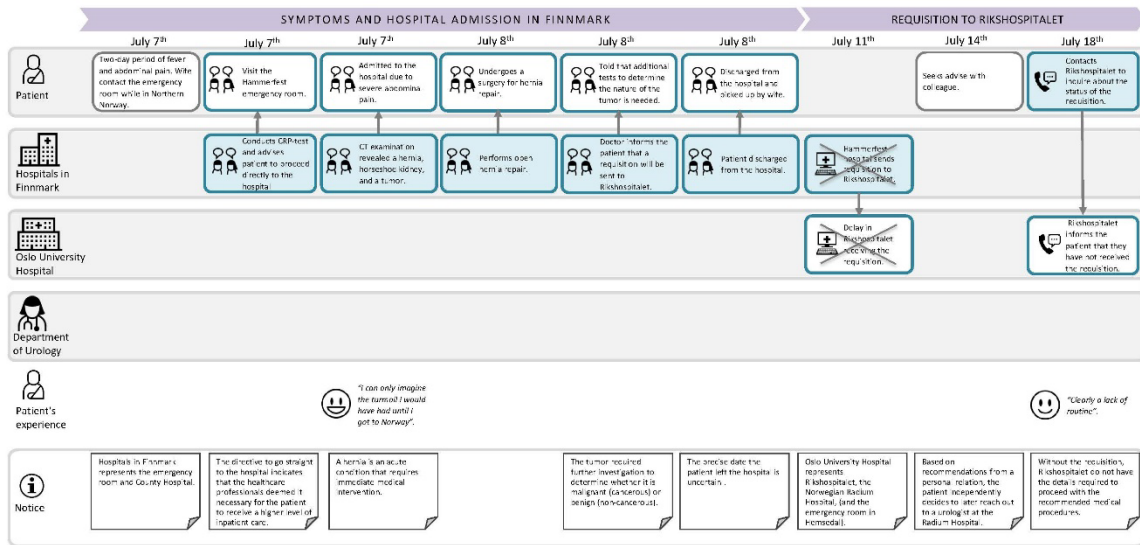
		Hva med å skape et i samarbeid med andre interessenter? Kan du initiere og opprette et pasientforløp på ditt institusjonsnivå, eller er det en ovenfra-og-ned-tilnærming?	
Forventede forbedringsområder	Ser du behov for en felles tilnærming til å beskrive pasientforløp – bestående av definisjoner, visualiseringer, ulike diagrammer og eksempler?		
	Hvordan vil du forbedre, eller gjøre pasientforløpet ditt enda bedre?	Hvis du trenger å forbedre det, hvilke områder vil du prioritere? I form av ... Måter å visualisere på? Utvide og samarbeide med andre institusjoner og helsetjenester? Bruk av digitale teknologier? Integrering i elektronisk pasientjournal? Tilgang til pasientene? Bedre overvåking- og evalueringssindikatorer? Måter å oppdatere på?	
For IT-personell	Er det noen modell og IT-struktur som er laget for å implementere pasientforløp?	Hvilket modelleringsspråk bruker du for å modellere pasientforløpet i institusjonen din? Kan du diskutere fordelene og begrensningene ved din modell og ditt modellingspråk?	
Konklusjon	Er det noe mer du vil legge til? Har du spørsmål eller kommentarer?		

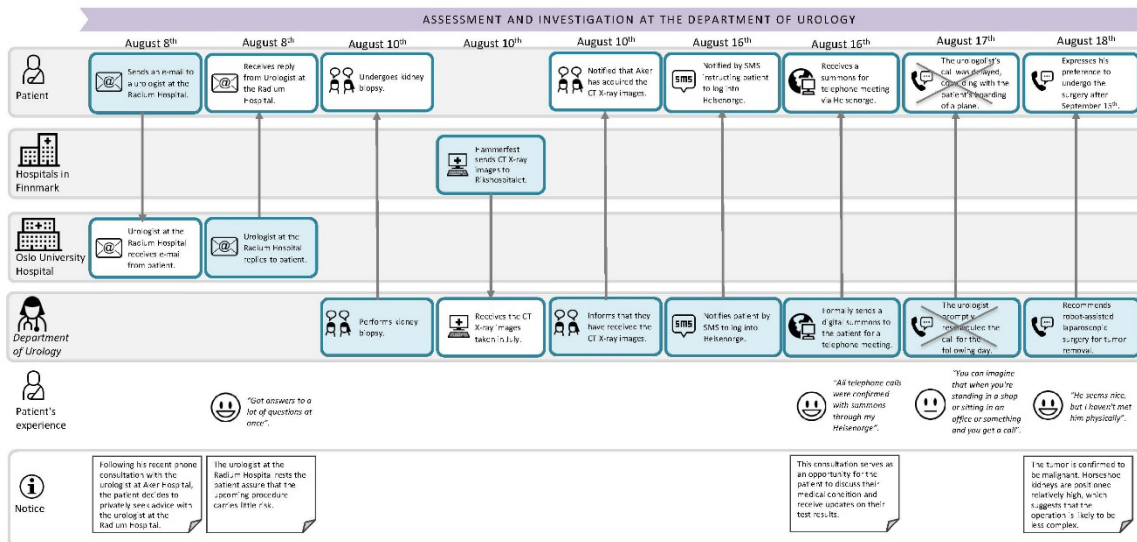
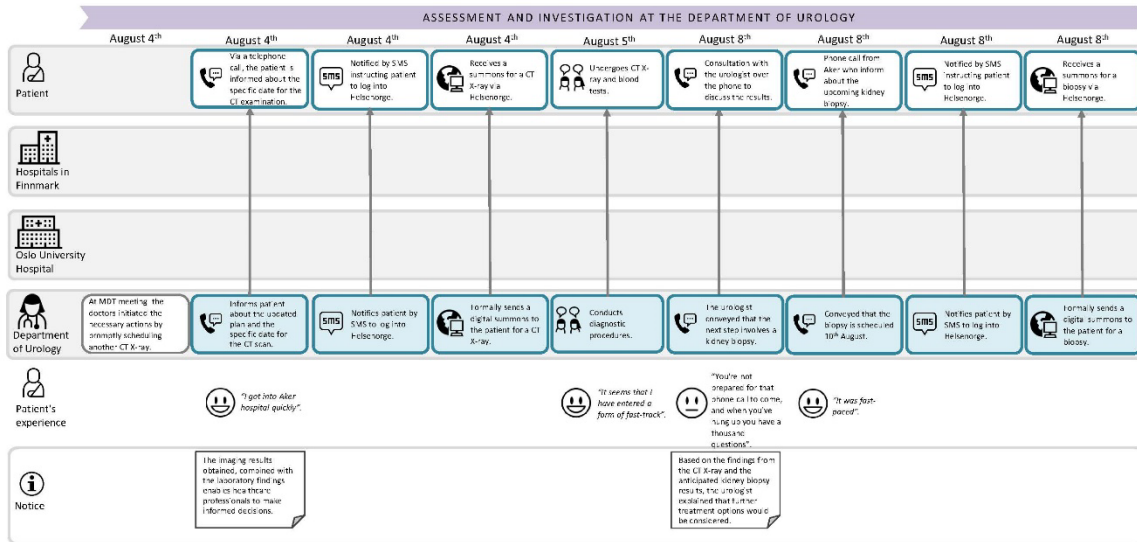
Tusen takk for at du tok deg tid til å svare på spørsmålene!

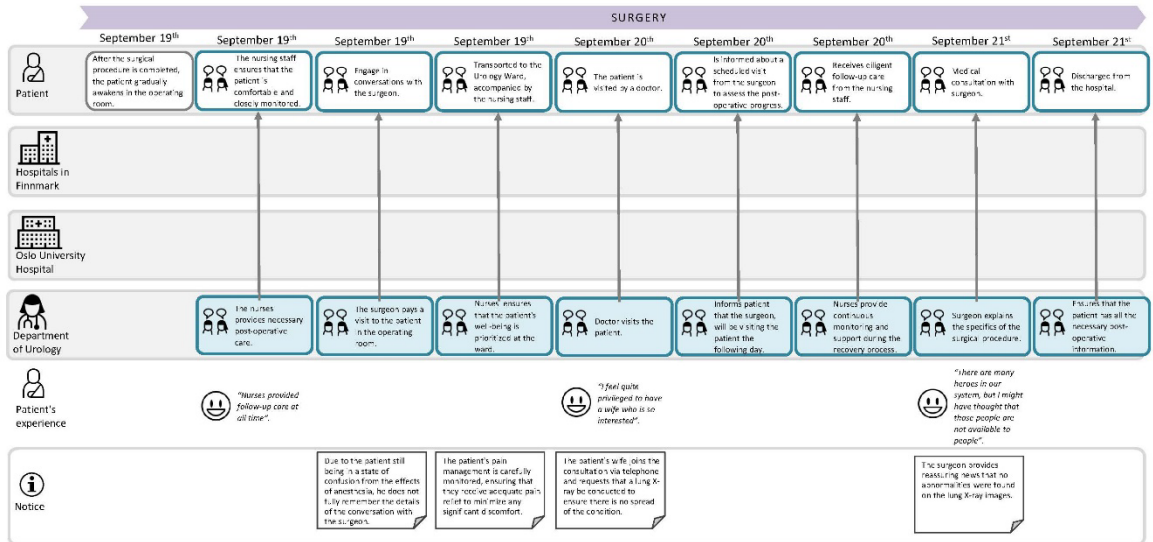
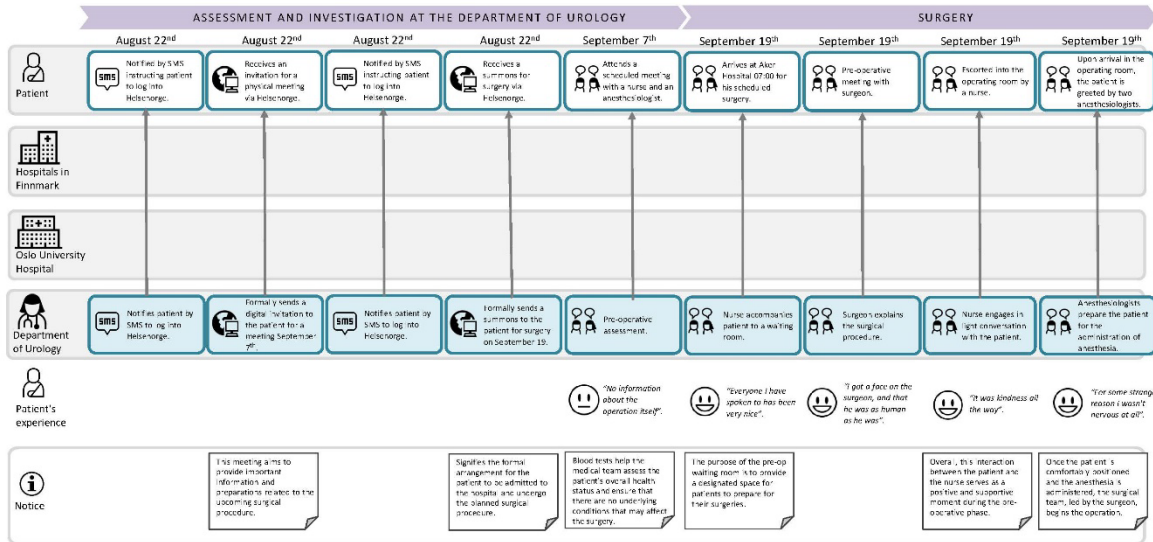
APPENDIX F: KIDNEY CANCER PATIENT PATHWAY

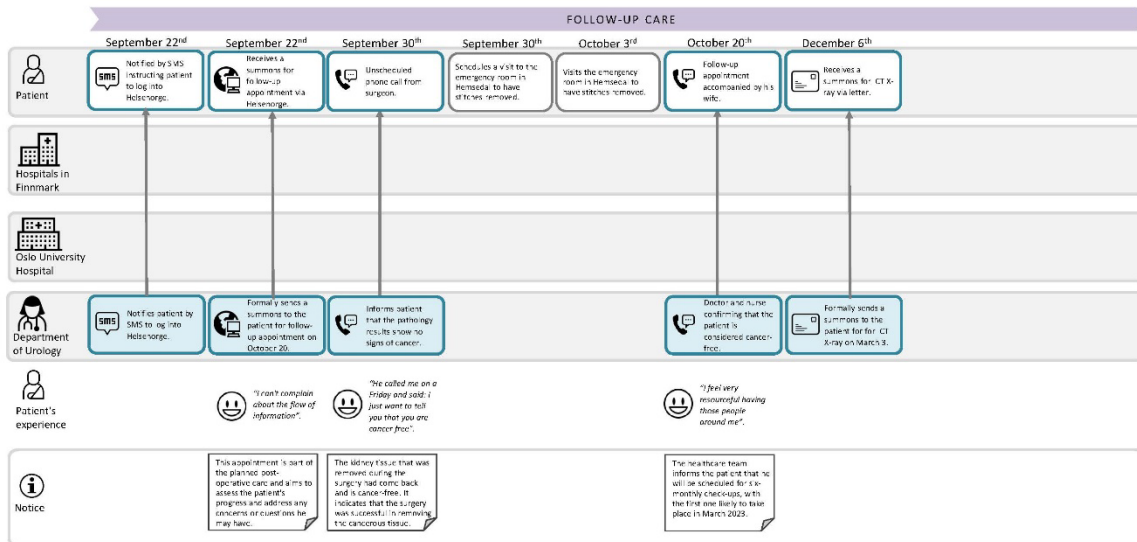


APPENDIX G: KIDNEY CANCER PATIENT JOURNEY









APPENDIX H: LONGITUDINAL MAPPING INFORMATION SHEET FOR TO CANCER PATIENTS



Forskningsprosjekt om pasientforløp

Vil du delta i forskningsprosjektet Pathway?

Begrepet pasientforløp omfatter pasientens mange møter og kontaktpunkter med helsevesenet gjennom en sykdomsperiode. I forskningsprosjektet Pathway ønsker vi å utvikle visuelle verktøy som skal gjøre det lettere å forstå og samarbeide om et pasientforløp på tvers av fag og roller i helsetjenesten. Dette også for å kunne kommunisere direkte med pasienter og deres pårørende.

Dette er et spørsmål til deg om å delta i forskningsaktiviteten der vi fokuserer på *pasienters egne erfaringer med pasientforløp*, hva slags informasjon man selv mener burde inngå, hvordan man ønsker å involveres i eget pasientforløp og hvordan informasjonen kan kommuniseres på tvers av tjenesteutøvere. Vi skal ikke fokusere på selve sykdommen eller hvordan den behandles.

Målgruppen i prosjektet er personer som lever med en sykdom samt deres pårørende. Du blir kontaktet fordi du har samtykket til at vi kan kontakte deg, gjennom din behandler ved Aker sykehus.

Hvem er ansvarlig for forskningsprosjektet

SINTEF Digital og Universitetet i Oslo (UiO) er ansvarlige for denne studien. Ansvarlig for gjennomføring av pasientstudien er forsker Anna Grøndahl Larsen ved SINTEF Digital. Prosjektleder er seniorforsker Ragnhild Halvorsrud ved SINTEF Digital. Masterstudenten Kristine Gjermestad ved Høyskolen i Innlandet er også en del av forskerteamet. Studien gjennomføres parallelt med forskningspartner Universitetet i Aalto, Finland. Prosjektet varer fra 1/8-2021 til 31/12-2025, og prosjektet mottar finansiell støtte fra Norges Forskningsråd.

Hva innebærer deltakelse for meg?

Som deltaker i prosjektet ønsker vi å **intervjue deg** om ditt pasientforløp og hvordan kommunikasjonen med helseaktørene fungerer. Vi vil ta notater og gjøre lydopptak under intervjuet. Deretter vil vi følge deg opp jevnlig i en periode på 2-4 måneder samtidig som **du fører en logg/dagbok** over alle kontaktpunkter med helsevesenet. En forsker vil følge deg opp jevnlig med påminnelser i denne perioden, og vil invitere deg til et **sluttintervju** for å gå gjennom materialet. Intervjuene tar 45-60 minutter og vil gjennomføres over telefon/Microsoft Teams. Ut over tidsbruk er det ingen ulemper assosiert med deltakelse i studien. Du vil motta et gavekort på kr. 750,- etter siste intervju.

Det er totalt 6-12 personer som skal delta i studien. I noen tilfeller ønsker vi også å **intervjue pårørende og behandlere**, men kun hvis du samtykker til det. Du vil styre *hvem* vi eventuelt henvender oss til. Dersom du samtykker til det vil vi involvere **pårørende** for å avlaste deg i loggføringen, og for å få ytterligere informasjon om kontakten med helsevesenet. I samtalen med **behandler** ønsker vi å forstå din behandlers rolle i ditt pasientforløp, hvordan de holder seg oppdatert om din behandling og hvordan de kommuniserer med deg og andre behandlere om ditt forløp.

Frivillig deltakelse

Det er frivillig å delta i studien. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Alle dine personopplysninger vil da bli slettet. Det vil ikke ha noen negative konsekvenser for deg og din behandling dersom du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger.

Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrevet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket. SINTEF og Universitetet i Oslo vil være behandlingsansvarlig for personopplysninger og datamateriale i denne studien. Det er kun

forskerteamet i SINTEF og UiO som vil ha tilgang til dine opplysninger. Du vil følges opp av én forsker gjennom perioden du deltar.

I noen tilfeller vil lydopptaket bli transkribert (registreres som tekst). Teksten vil i så fall anonymiseres ved at eventuelle personidentifiserbare opplysninger fjernes. Transkribering gjennomføres da av et norsk selskap (f.eks Troll i Ord) i henhold til databehandleravtale med SINTEF/UiO; i databehandleravtalen forplikter selskapet seg til å behandle lydopptaket fortrolig og sikkert, og til å slette materialet umiddelbart etter at transkribering er gjennomført.

Datamaterialet vil bli oppbevart på krypterte og godkjente datamaskiner og skytjenester. Som en ekstra beskyttelse vil ditt navn og kontaktinformasjon oppbevares separat fra resten av datamaterialet. Alle data vil bli anonymisert før bruk i prosjektets publikasjoner og presentasjoner. Det vil ikke være mulig å spore noe tilbake til deg som person.

Hva skjer med opplysningene om meg? Hvilke rettigheter har jeg?

Opplysningene om deg anonymiseres når prosjektet avsluttes, og senest innen utgangen av 2025. Navnelister, koblingsnøkler (som viser til koblingen mellom datamaterialet og deg) og lydopptak vil samtidig bli slettet. Alle data anonymiseres før bruk i prosjektets publikasjoner og presentasjoner. Det vil ikke være mulig å spore noe tilbake til deg som person.

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg, og å få utlevert en kopi av opplysningene,
- å få rettet personopplysninger om deg,
- å få slettet personopplysninger om deg, og
- å sende klage til Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?

Vi behandler opplysninger om deg basert på ditt samtykke. Norsk senter for forskningsdata AS (NSD) har vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Spørsmål?

Har du spørsmål til studien rundt prosjektmål, lagring av data eller annet kan du kontakte prosjektleder Ragnhild Halvorsrud, epost: ragnhild.halvorsrud@sintef.no, mobil +47 977 38 883 eller personvernkoordinator i SINTEF, Jan Wåge, e-post Jan.Wage@sintef.no, telefon 405 56 650.

Har du spørsmål knyttet til NSD sin vurdering av prosjektet kan du ta kontakt med NSD på epost: personverntjenester@nsd.no eller på telefon: 55 58 21 17.

Vennlig hilsen

<NN> ved <SINTEF/UiO>
Forsker som vil følge deg opp

Ragnhild Halvorsrud, SINTEF Digital
Prosjektleder for Pathway

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet Pathway, og har fått anledning til å stille spørsmål. Jeg samtykker til følgende:

- å delta i studien, som omfatter to intervjuer samt loggføring over 2-4 måneder.
- at min pårørende kan gi opplysninger om meg til prosjektet (fyll ut kontaktinfo under)
- at min behandler kan gi opplysninger om meg til prosjektet (fyll ut kontaktinfo under), og dermed fritas fra sin taushetsplikt slik at de kan bidra med informasjon

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet

Navn i blokkbokstaver:

Dato og signatur:

(Dato)

(Signatur - prosjektdeltaker)

Hvis aktuelt: Kontaktinformasjon til min pårørende

Navn:
Telefon:
E-post:

Hvis aktuelt: Kontaktinformasjon til min behandler:

Navn og rolle:
Telefon:
E-post:

APPENDIX I: LONGITUDINAL MAPPING INFORMATION SHEET TO MS PATIENTS



Forskningsprosjekt om pasientforløp

Vil du delta i forskningsprosjektet Pathway?

Begrepet pasientforløp omfatter pasientens mange møter og kontaktpunkter med helsevesenet gjennom en sykdomsperiode. I forskningsprosjektet Pathway ønsker vi å utvikle visuelle verktøy som skal gjøre det lettere å forstå og samarbeide om et pasientforløp på tvers av fag og roller i helsetjenesten. Dette også for å kunne kommunisere direkte med pasienter og deres pårørende.

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Målgruppen i prosjektet er personer som lever med en sykdom samt deres pårørende.

Hvem er ansvarlig for forskningsprosjektet

SINTEF Digital og Universitetet i Oslo (UiO) er ansvarlige for denne studien. Ansvarlig for gjennomføring av pasientstudien er forsker Anna Grøndahl Larsen ved SINTEF Digital. Prosjektleder er seniorforsker Ragnhild Halvorsrud ved SINTEF Digital. Masterstudenten Kristine Gjermestad ved Høyskolen i Innlandet er også en del av forskerteamet. Studien gjennomføres parallelt med forskningspartner Universitetet i Aalto, Finland. Prosjektet varer fra 1/8-2021 til 31/12-2025, og prosjektet mottar finansiell støtte fra Norges Forskningsråd.

Hva innebærer deltakelse for meg?

Som deltaker i prosjektet ønsker vi å **intervjue deg** om ditt pasientforløp og hvordan kommunikasjonen med helseaktørene fungerer. Vi vil ta notater og gjøre lydopptak under intervjuet. Deretter vil vi følge deg opp jevnlig i en periode på 2-4 måneder samtidig som **du fører en logg/dagbok** over alle kontaktpunkter med helsevesenet. En forsker vil følge deg opp jevnlig med påminnelser i denne perioden, og vil invitere deg til et **sluttintervju** for å gå gjennom materialet. Intervjuene tar 45-60 minutter og vil gjennomføres over telefon/Microsoft Teams. Ut over tidsbruk er det ingen ulemper assosiert med deltakelse i studien. Du vil motta et gavekort på kr. 750,- etter siste intervju.

Det er totalt 6-12 personer som skal delta i studien. I noen tilfeller ønsker vi også å **intervjue pårørende og behandlere**, men kun hvis du samtykker til det. Du vil styre *hvem* vi eventuelt henvender oss til. Dersom du samtykker til det vil vi involvere **pårørende** for å avlaste deg i loggføringen, og for å få ytterligere informasjon om kontakten med helsevesenet. I samtalen med **behandler** ønsker vi å forstå din behandlers rolle i ditt pasientforløp, hvordan de holder seg oppdatert om din behandling og hvordan de kommuniserer med deg og andre behandlere om ditt forløp.

Frivillig deltakelse

Det er frivillig å delta i studien. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Alle dine personopplysninger vil da bli slettet. Det vil ikke ha noen negative konsekvenser for deg og din behandling dersom du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger.

Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrevet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket. SINTEF og Universitetet i Oslo vil være behandlingsansvarlig for personopplysninger og datamateriale i denne studien. Det er kun

forskerteamet i SINTEF og UiO som vil ha tilgang til dine opplysninger. Du vil følges opp av én forsker gjennom perioden du deltar.

I noen tilfeller vil lydopptaket bli transkribert (registreres som tekst). Teksten vil i så fall anonymiseres ved at eventuelle personidentifiserbare opplysninger fjernes. Transkribering gjennomføres da av et norsk selskap (f.eks Troll i Ord) i henhold til databehandleravtale med SINTEF/UiO; i databehandleravtalen forplikter selskapet seg til å behandle lydopptaket fortrolig og sikkert, og til å slette materialet umiddelbart etter at transkribering er gjennomført.

Datamaterialet vil bli oppbevart på krypterte og godkjente datamaskiner og skytjenester. Som en ekstra beskyttelse vil ditt navn og kontaktinformasjon oppbevares separat fra resten av datamaterialet. Alle data vil bli anonymisert før bruk i prosjektets publikasjoner og presentasjoner. Det vil ikke være mulig å spore noe tilbake til deg som person.

Hva skjer med opplysningene om meg? Hvilke rettigheter har jeg?

Opplysningene om deg anonymiseres når prosjektet avsluttes, og senest innen utgangen av 2025. Navnelister, koblingsnøkler (som viser til koblingen mellom datamaterialet og deg) og lydopptak vil samtidig bli slettet. Alle data anonymiseres før bruk i prosjektets publikasjoner og presentasjoner. Det vil ikke være mulig å spore noe tilbake til deg som person.

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg, og å få utlevert en kopi av opplysningene,
- å få rettet personopplysninger om deg,
- å få slettet personopplysninger om deg, og
- å sende klage til Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?

Vi behandler opplysninger om deg basert på ditt samtykke. Norsk senter for forskningsdata AS (NSD) har vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Spørsmål?

Har du spørsmål til studien rundt prosjektmål, lagring av data eller annet kan du kontakte prosjektleder Ragnhild Halvorsrud, epost: ragnhild.halvorsrud@sintef.no, mobil +47 977 38 883 eller personvernkoordinator i SINTEF, Jan Wåge, e-post Jan.Wage@sintef.no, telefon 405 56 650.

Har du spørsmål knyttet til NSD sin vurdering av prosjektet kan du ta kontakt med NSD på epost: personverntjenester@nsd.no eller på telefon: 55 58 21 17.

Vennlig hilsen

<NN> ved <SINTEF/UiO>
Forsker som vil følge deg opp

Ragnhild Halvorsrud, SINTEF Digital
Prosjektleder for Pathway

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet Pathway, og har fått anledning til å stille spørsmål. Jeg samtykker til følgende:

- å delta i studien, som omfatter to intervjuer samt loggføring over 2-4 måneder.
- at min pårørende kan gi opplysninger om meg til prosjektet (fyll ut kontaktinfo under)
- at min behandler kan gi opplysninger om meg til prosjektet (fyll ut kontaktinfo under), og dermed fritas fra sin taushetsplikt slik at de kan bidra med informasjon

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet

Navn i blokkbokstaver:

Dato og signatur:

(Dato)

(Signatur - prosjektdeltaker)

Hvis aktuelt: Kontaktinformasjon til min pårørende

Navn:

Telefon:

E-post:

Hvis aktuelt: Kontaktinformasjon til min behandler:

Navn og rolle:

Telefon:

E-post:

APPENDIX J: LONGITUDINAL MAPPING INFORMATION SHEET FOR TO NEXT-OF-KINS



Forskningsprosjekt om pasientforløp

Vil du delta i forskningsprosjektet Pathway?

Begrepet pasientforløp omfatter pasientens mange møter og kontaktpunkter med helsevesenet gjennom en sykdomsperiode. I forskningsprosjektet Pathway ønsker vi å utvikle visuelle verktøy som skal gjøre det lettere å forstå og samarbeide om et pasientforløp på tvers av fag og roller i helsetjenesten. Dette også for å kunne kommunisere direkte med pasienter og deres pårørende.

Dette er et spørsmål til deg om å delta i forskningsaktiviteten der vi fokuserer på *pasienters egne erfaringer med pasientforløp*, hva slags informasjon man selv mener burde inngå, hvordan man ønsker å involveres i eget pasientforløp og hvordan informasjonen kan kommuniseres på tvers av tjenesteutøvere. Vi skal ikke fokusere på selve sykdommen eller hvordan den behandles.

Målgruppen i prosjektet er personer som lever med en sykdom samt deres pårørende. Vi har fått din kontaktinformasjon gjennom<NN> som har oppgitt deg som pårørende.

Hvem er ansvarlig for forskningsprosjektet

SINTEF Digital og Universitetet i Oslo (UiO) er ansvarlige for denne studien. Ansvarlig for gjennomføring av pasientstudien er forsker Anna Grøndahl Larsen ved SINTEF Digital. Prosjektleder er seniorforsker Ragnhild Halvorsrud ved SINTEF Digital. Masterstudenten Kristine Gjermestad ved Høyskolen i Innlandet er også en del av forskerteamet. Studien gjennomføres parallelt med forskningspartner Universitetet i Aalto, Finland. Prosjektet varer fra 1/8-2021 til 31/12-2025, og prosjektet mottar finansiell støtte fra Norges Forskningsråd.

Hva innebærer deltakelse for meg?

Som en del av prosjektet skal vi gjennomføre intervjuer og kartlegge pasientforløpet til personer som lever med sykdom. Vi ønsker også å belyse pasientforløpet fra perspektivet til pårørende. Hvis du velger å delta, ønsker vi å **intervjue deg**. Intervjuet vil vare i cirka 45-60 minutter og vil gjennomføres over telefon/Microsoft Teams.

Vi vil ta notater og gjøre lydopptak under intervjuet. Det vi ønsker å spørre deg som pårørende om er: Hvordan opplever du å støtte en som lever med sykdom? På hvilken måte bistår du med å holde oversikt over kommunikasjon og kontaktpunkter med helseaktørene? Hvordan blir du, som pårørende, informert om pasientforløpet? Hvilke verktøy kunne gjort det lettere å holde oversikt over pasientforløpet?

I tillegg til å delta i et intervju ønsker vi at du **bistår med loggføring** av pasientforløpet gjennom en periode på 2-4 måneder.

Ut over tidsbruk er det ingen ulemper assosiert med deltakelse i studien.

Frivillig deltakelse

Det er frivillig å delta i studien. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Alle dine personopplysninger vil da bli slettet. Det vil ikke ha noen negative konsekvenser for deg og din behandling dersom du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger.

Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrevet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket. SINTEF og Universitetet i Oslo vil være behandlingsansvarlig for personopplysninger og datamateriale i denne studien. Det er kun

forskerteamet i SINTEF og UiO som vil ha tilgang til dine opplysninger. Du vil følges opp av én forsker gjennom perioden du deltar.

I noen tilfeller vil lydopptaket bli transkribert (registreres som tekst). Teksten vil i så fall anonymiseres ved at eventuelle personidentifiserbare opplysninger fjernes. Transkribering gjennomføres da av et norsk selskap (f.eks Troll i Ord) i henhold til databehandleravtale med SINTEF/UiO; i databehandleravtalen forplikter selskapet seg til å behandle lydopptaket fortrolig og sikkert, og til å slette materialet umiddelbart etter at transkribering er gjennomført.

Datamaterialet vil bli oppbevart på krypterte og godkjente datamaskiner og skytjenester. Som en ekstra beskyttelse vil ditt navn og kontaktinformasjon oppbevares separat fra resten av datamaterialet. Alle data vil bli anonymisert før bruk i prosjektets publikasjoner og presentasjoner. Det vil ikke være mulig å spore noe tilbake til deg som person.

Hva skjer med opplysningene om meg? Hvilke rettigheter har jeg?

Opplysningene om deg anonymiseres når prosjektet avsluttes, og senest innen utgangen av 2025. Navnelister, koblingsnøkler (som viser til koblingen mellom datamateriale og deg) og lydopptak vil samtidig bli slettet. Alle data anonymiseres før bruk i prosjektets publikasjoner og presentasjoner. Det vil ikke være mulig å spore noe tilbake til deg som person.

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg, og å få utlevert en kopi av opplysningene,
- å få rettet personopplysninger om deg,
- å få slettet personopplysninger om deg, og
- å sende klage til Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?

Vi behandler opplysninger om deg basert på ditt samtykke. Norsk senter for forskningsdata AS (NSD) har vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Spørsmål?

Har du spørsmål til studien rundt prosjektmål, lagring av data eller annet kan du kontakte prosjektleder Ragnhild Halvorsrud, epost: ragnhild.halvorsrud@sintef.no, mobil +47 977 38 883 eller personvernkoordinator i SINTEF, Jan Wåge, e-post Jan.Wage@sintef.no, telefon 405 56 650.

Har du spørsmål knyttet til NSD sin vurdering av prosjektet kan du ta kontakt med NSD på epost: personverntjenester@nsd.no eller på telefon: 55 58 21 17.

Vennlig hilsen

<NN> ved <SINTEF/UiO>
Forsker som vil følge deg opp

Ragnhild Halvorsrud, SINTEF Digital
Prosjektleder for Pathway

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet Pathway, og har fått anledning til å stille spørsmål. Jeg samtykker til følgende:

å delta på intervju

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet

Navn i blokkbokstaver:

Dato og signatur:

(Dato)

(Signatur – prosjektdeltaker)

APPENDIX K: LONGITUDINAL MAPPING INFORMATION SHEET FOR TO TREATING PHYSICIANS



Forskningsprosjekt om pasientforløp

Vil du delta i forskningsprosjektet Pathway?

Begrepet pasientforløp omfatter pasientens mange møter og kontaktpunkter med helsevesenet gjennom en sykdomsperiode. I forskningsprosjektet Pathway ønsker vi å utvikle visuelle verktøy som skal gjøre det lettere å forstå og samarbeide om et pasientforløp på tvers av fag og roller i helsetjenesten. Dette også for å kunne kommunisere direkte med pasienter og deres pårørende.

Dette er et spørsmål til deg om å delta i forskningsaktiviteten der vi fokuserer på *pasienters egne erfaringer med pasientforløp*, hva slags informasjon man selv mener burde inngå, hvordan man ønsker å involveres i eget pasientforløp og hvordan informasjonen kan kommuniseres på tvers av tjenesteutøvere. Vi skal ikke fokusere på selve sykdommen eller hvordan den behandles.

Målgruppen i prosjektet er personer som lever med en sykdom samt deres pårørende og behandler. Vi har fått din kontaktinformasjon gjennom et intervju med<NN>... som har oppgitt deg som behandler.

Hvem er ansvarlig for forskningsprosjektet

SINTEF Digital og Universitetet i Oslo (UiO) er ansvarlige for denne studien. Prosjektleder er seniorforsker Ragnhild Halvorsrud ved SINTEF Digital. Studien gjennomføres parallelt med forskningspartner Universitetet i Aalto, Finland. Prosjektet varer fra 1/8-2021 til 31/12-2025, og prosjektet mottar finansiell støtte fra Norges Forskningsråd.

Hva innebærer deltakelse for meg?

Som en del av prosjektet skal vi gjennomføre intervjuer og kartlegge pasientforløpet til personer som lever med sykdom. Vi ønsker også å belyse pasientforløpet fra perspektivet til pårørende og behandlere. Hvis du velger å delta, gjennomfører vi et **intervju** som tar 45-60 minutter. Intervjuet vil gjennomføres fysisk eller over telefon/Microsoft Teams. Vi vil ta notater og gjøre lydopptak under intervjuet.

Det vi ønsker å spørre deg som behandler om:

- Hvordan bruker dere begrepet pasientforløp?
- Hvilke andre aktører er involvert i behandlingen av NN, og hvordan dere kommuniserer?
- Hvilke IT-systemer som er involvert i pasientforløpet til NN? Hvilken type informasjon som lagres.
- Hvilke verktøy kunne gjort det lettere å holde oversikt over pasientforløpet?

Ut over tidsbruk er det ingen ulemper assosiert med deltakelse i studien. Det er totalt 6-12 pasienter som skal delta i studien.

Frivillig deltakelse

Det er frivillig å delta i studien. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du kan når som helst trekke ditt samtykke uten å oppgi noen grunn. Alle dine personopplysninger vil da bli slettet. Det vil ikke ha noen negative konsekvenser for deg dersom du ikke vil delta eller senere velger å trekke deg.

Ditt personvern – hvordan vi oppbevarer og bruker dine opplysninger.

Vi vil bare bruke opplysningene om deg til formålene vi har fortalt om i dette skrevet. Vi behandler opplysningene konfidensielt og i samsvar med personvernregelverket. SINTEF og Universitetet i Oslo vil være behandlingsansvarlig for personopplysninger og datamateriale i denne studien. Det er kun

forskerteamet i SINTEF og UiO som vil ha tilgang til dine opplysninger. Du vil følges opp av én forsker gjennom perioden du deltar.

I noen tilfeller vil lydopptaket bli transkribert (registreres som tekst). Teksten vil i så fall anonymiseres ved at eventuelle personidentifiserbare opplysninger fjernes. Transkribering gjennomføres da av et norsk selskap (f.eks Troll i Ord) i henhold til databehandleravtale med SINTEF/UiO; i databehandleravtalen forplikter selskapet seg til å behandle lydopptaket fortrolig og sikkert, og til å slette materialet umiddelbart etter at transkribering er gjennomført.

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Hva skjer med opplysningene om meg? Hvilke rettigheter har jeg?

Opplysningene om deg anonymiseres når prosjektet avsluttes, og senest innen utgangen av 2025. Navnelister, koblingsnøkler (som viser til koblingen mellom datamateriale og deg) og lydopptak vil samtidig bli slettet. Alle data anonymiseres før bruk i prosjektets publikasjoner og presentasjoner. Det vil ikke være mulig å spore noe tilbake til deg som person.

Så lenge du kan identifiseres i datamaterialet, har du rett til:

- innsyn i hvilke personopplysninger som er registrert om deg, og å få utlevert en kopi av opplysningene,
- å få rettet personopplysninger om deg,
- å få slettet personopplysninger om deg, og
- å sende klage til Datatilsynet om behandlingen av dine personopplysninger.

Hva gir oss rett til å behandle personopplysninger om deg?

Vi behandler opplysninger om deg basert på ditt samtykke. Norsk senter for forskningsdata AS (NSD) har vurdert at behandlingen av personopplysninger i dette prosjektet er i samsvar med personvernregelverket.

Spørsmål?

Har du spørsmål til studien rundt prosjektmål, lagring av data eller annet kan du kontakte prosjektleder Ragnhild Halvorsrud, epost: ragnhild.halvorsrud@sintef.no, mobil +47 977 38 883 eller personvernkoordinator i SINTEF, Jan Wåge, e-post Jan.Wage@sintef.no, telefon 405 56 650.

Har du spørsmål knyttet til NSD sin vurdering av prosjektet kan du ta kontakt med NSD på epost: personverntjenester@nsd.no eller på telefon: 55 58 21 17.

Vennlig hilsen

<NN> ved <SINTEF/UiO>
Forsker som vil følge deg opp

Ragnhild Halvorsrud, SINTEF Digital
Prosjektleder for Pathway

Samtykkeerklæring

Jeg har mottatt og forstått informasjon om prosjektet Pathway, og har fått anledning til å stille spørsmål. Jeg samtykker til følgende:

å delta på intervju

Jeg samtykker til at mine opplysninger behandles frem til prosjektet er avsluttet

Navn i blokkbokstaver:

Dato og signatur:

(Dato)

(Signatur - prosjektdeltaker)

APPENDIX L: DIARY FOR MS PATIENTS

Ha dette skjemaet lett
tilgjengelig og fyll ut
fortløpende!

Strukturert dagbok



Fyll ut én rad i skjemaet hver gang ..

- du er i kontakt med helsetjenesten (f.eks. konsultasjon, brev, innkalling, telefon, oppmøte, SMS)
- du har en aktivitet som er relevant for sykdommen (trening, legebesøk, informasjonssøking, digitalt hjelpemiddel)
- Alt du synes er relevant kan du loggføre (bedre med for mye enn for lite)



Vi holder kontakt underveis ...

- .. for å høre siste nytt
- .. for å avtale neste steg



Til sist ringer vi deg for et avslutningsintervju ..

- .. der vi går gjennom dagboken din
- Deretter sender vi deg gavekort

Takk for at du hjelper oss.
Ditt bidrag er viktig for vår
forskning! Ta kontakt hvis du
lurer på noe.












Anna Grøndahl Larsen
Mobil: 977 23 526
e-post: anna.g.larsen@sintef.no

Eksempel



Dato og tid	Kontakt Aktør Hendelse	HVA SKJEDDE? OPPLEVELSE OG FORVENTNING? FORSLAG TIL FORBEDRING?	Kryss av
12. nov kl. 11:30	Brev fra MS- klinikken	Jeg fikk innkalling til time hos MS- klinikken. Tidspunktet passet ikke	<input type="checkbox"/> <input type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
13.nov kl. 13:30	Telefon	Jeg ringte MS-klinikken for å bytte timen ... Fikk vite at ... Derfor fant vi ut at ... Dette synes jeg var bra, fordi ...	<input type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
15. nov. Kveld	Hendelse Egne tanker Etc.	Denne dagen var spesiell fordi ... Jeg opplevde det som ... Dette hadde vært fint hvis ... Jeg savner informasjon om ...	<input type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
21. nov. kl.13:35	E-post fra fysioterapeut	Jeg mottok en melding fra ... Det handlet om ...	<input type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
30. nov kl. 09:30	Konsultasjon	Jeg møtte opp på ... Jeg opplevde kommunikasjonen med legen som ... Sykepleieren var ... Jeg skulle ønske at jeg fikk vite mer om ...	<input type="checkbox"/> <input type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Start å fylle ut på denne siden

Dato og tid	Kontakt Aktør Hendelse	HVA SKJEDDE? OPPLEVELSE OG FORVENTNING? FORSLAG TIL FORBEDRING?	Kryss av
			<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>     
			<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>     
			<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>     

APPENDIX M: START INTERVIEW GUIDE FOR MS PATIENTS

Startintervju – pasient

Målgruppe: pasienter som skal delta i longitudinell studie. Pasientene intervjues ved oppstart/inkludering i studien, de inviteres til å føre dagbok, og til et avslutningsintervju. Intervjuet gjennomføres over Microsoft Teams.

Hovedtemaer:

- Innledning til intervju
- Intro om pasient
- Intro om sykdom: Hva har skjedd hittil? Hvordan oppleves kommunikasjonen?
- Pårørende og dokumentasjon
- Instruksjon i bruk av dagbok
- Involvering av pårørende og behandler (der det er aktuelt)

Informasjon til intervjuer	Script med spørsmål	Notatfelt
Husk å sette på lydopptaker!	<p>Innledning til intervju</p> <p>Takk for at du har takket ja til å delta i studien.</p> <p>For å repetere kort om formålet med prosjektet så omfatter begrepet pasientforløp altså pasientens mange møter og kontaktpunkter med helsevesenet gjennom en sykdomsperiode. I forskningsprosjektet Pathway ønsker vi å utvikle visuelle verktøy som skal gjøre det lettere å forstå og samarbeide om et pasientforløp på tvers av fag og roller i helsetjenesten. Dette også for å kunne kommunisere direkte med pasienter og deres pårørende.</p> <p>Som del av dette, fokuserer vi i studien på <i>pasienters egne erfaringer med pasientforløp</i>, hva slags informasjon man selv mener burde inngå, hvordan man ønsker å involveres i eget pasientforløp og hvordan informasjonen kan kommuniseres på tvers av tjenesteutøvere.</p>	

	<p>Formålet med dette første intervjuet er at vi får vite litt om deg og ditt pasientforløp så langt.</p> <p>Hvis det er greit for deg starter jeg lydopptaket nå?</p>	
	Intro om pasient	
Formål: danne oss et bedre bilde av hvem deltageren er. Ikke behov for å gå i dybden her.	<p><i>Bakgrunn (kort)</i></p> <ul style="list-style-type: none"> • Først lurer jeg på om du kan fortelle kort om deg og din familie- og jobbsituasjon? (heltid/deltid/pensjonist). • Hvordan ser hverdagen din ut? 	
	Intro om sykdom: Hva har skjedd hittil? Hvordan oppleves kommunikasjonen?	
<p>Formål: få en oversikt over hva som har skjedd til nå i pasientforløpet, med vekt på mer eller mindre faste kontaktpunkter deltageren har og hva som har skjedd de siste par ukene.</p> <p>Vi lar deltageren fortelle først, mens vi tar notater. Deretter går vi tilbake og tar deltageren steg for steg gjennom det de har fortalt slik at de kan utdype hva som skjedde og hvordan de opplevde de ulike kontaktpunktene.</p>	<p><i>Om sykdom og kartlegging av involverte aktører – behandling og oppfølging:</i></p> <ul style="list-style-type: none"> • Kan du fortelle kort historien om sykdommen din og forløpet så langt. Når fikk du diagnosen? Hva har skjedd siden da? (i korte trekk) • Hva slags kontaktpunkter har du i dag når det gjelder behandling og oppfølging? Er det noen du treffer regelmessig? (fastlege, nevrolog, fysioterapeut, ergoterapeut, andre tjenester, NAV, pasientorganisasjon, privat osv.). • Kan du fortelle tilbake fra de siste to ukene? Hva har skjedd, hvem har du vært i kontakt med? (oppmøte, telefon, brev, påminnelse) • Har du en kontaktperson eller koordinator? <p><Gå tilbake og ta deltageren gjennom pasientforløpet de siste ukene steg for steg, av typen «ok, du har altså vært i kontakt med fastlege, ergoterapeut ...». «Hvordan opplevde du kontakten?» ...></p>	

	<ul style="list-style-type: none"> Vet du hva som skjer fremover de neste ukene, har du planlagte kontaktpunkter med helsevesenet? 	
	<i>Kommunikasjon med aktørene i helsetjenesten</i> <ul style="list-style-type: none"> Hvordan opplever du kontakten med helsetjenesten? Opplevs det koordinert eller fragmentert? Får du den informasjonen du trenger? 	
	Pårørende og dokumentasjon	
	<i>Pårørende</i> <ul style="list-style-type: none"> Har du pårørende som støtter/bistår deg gjennom behandling og oppfølging? Hvis ja: er pårørende involvert i møtet med helsetjenesten? (er de med på konsultasjoner eller involvert på andre måter) 	
	<i>Dokumentasjon av egen sykdom</i> <ul style="list-style-type: none"> Noterer du noe om din sykdom, f.eks. en logg eller dagbok? Hvis ja, hvordan (papir, mobil, pc, app? og hvor ofte? 	
	<ul style="list-style-type: none"> Til slutt: Hva er dine forventinger til å være med i studien? 	
Intervjuer deler skjerm med deltageren slik at de kan se dagboken (dersom intervjuet gjennomføres via Teams). Intervjuer viser deltageren	Instruksjon i bruk av dagbok Jeg skal nå gå gjennom utfyllingen av dagboken/loggen du skal føre. <forklare eller vise hvordan dagboken ser ut>	

<p>dagboken og forklarer hvordan dagboken er utformet og fylles ut</p> <p>Start med å gå gjennom punktene på side 1 og 2 i dagboken.</p> <p>I sum er vi interessert i at deltageren noterer i dagboken: hva skjedde og når? Hvordan skjedde informasjonen/kommunikasjonen? Hvem tok kontakt med hvem? Hvordan opplevde deltageren dette? Var kommunikasjonen god? Er det informasjon deltageren savner?</p> <p>Husk å avklare spørsmål underveis.</p>	<p>Du skal fylle ut én rad i skjemaet hver gang</p> <ul style="list-style-type: none"> Du er i kontakt med helsetjenesten (konsultasjon, brev, innkalling, telefon, oppmøte, SMS) Du har en aktivitet som er relevant for sykdommen (trening, legebesøk, informasjonssøking etc.) Du fyller ut dato, hvem du er i kontakt med, hvordan kontakten foregikk (e-post, oppmøte etc.) I tillegg til hva som skjedde, har dagboken et felt der vi ønsker at du skriver hvordan du opplevde hendelsen. Dette kan inkludere hvordan du opplevde møtet med og informasjonen fra en lege, i en innkalling eller lignende, eller hvordan du opplever kommunikasjonen mellom ulike deler av helsetjenesten. <p>Du kan også gjærne skrive inn sykdomsrelaterte hendelser utover direkte kontakt med helsetjenesten. Som for eksempel inkludere egne søk på nett, hendelser underveis og hva som evt. gjør at du er fornøyd/mindre fornøyd med informasjonen du sitter på.</p> <p>Husk at eksempelet på hvordan dagboken kan fylles ut, nettopp er et eksempel, og ikke en mal for hvilke formuleringer du må bruke når de skriver dagboken. Du kan f.eks. gjerne skrive mer utfyllende. Det er bedre med for mye enn for lite informasjon: dersom du tror noe er relevant, men ikke er helt sikker, er det bedre at du noterer det i dagboken enn at du ikke noterer det.</p>	
	Vi vil gjerne at du fyller ut dagboken regelmessig .	

	Nå når du får dagboken tilsendt, ønsker vi også gjerne at du fyller inn dagboken fra to uker tilbake i tid så godt du klarer/husker.	
Dersom deltageren ønsker å fylle ut dagboken på papir (og de ikke ønsker å printe ut selv), sender vi dem dagboken i posten. Husk da å be om postadresse. Dersom deltageren ønsker å fylle ut dagboken digitalt, sender vi dem dagboken på e-post.	<i>Alternativer til utfylling av dagbok</i> <ul style="list-style-type: none"> Hvordan vil du helst fylle ut dagboken, på papir eller på PC? 	
Retur av dagbok til oss: dagboken inneholder nå ikke informasjon om hvordan dagboken returneres til oss. Vi tar sikte på at deltageren returnerer dagboken hver/annen hver uke. Parallelt med at vi følger opp deltageren underveis, kan vi be dem om å returnere dagboken.	<i>Oppfølging underveis</i> <ul style="list-style-type: none"> Vi vil gjerne følge deg opp underveis. Hvordan ønsker du at vi holder kontakt deg underveis med påminnelser og for å høre hvordan det går? (på telefon, SMS, epost) Vi kan tilpasse dette litt underveis, men vi følger deg gjerne opp mer hyppig i perioder hvor det skjer mer, du er i kontakt med helsevesenet, til behandling eller lignende. Du kan gjerne løpende returnere dagboken til oss via e-post. Vi tar kontakt med deg angående retur av dagboken underveis. 	
	<i>Avslutningsintervju</i> Etter 2-4 måneder kontakter vi deg for et avslutningsintervju.	
	<ul style="list-style-type: none"> Har du noen spørsmål? 	
	Involvering av pårørende og behandler (hvis aktuelt)	

KUN RELEVANT HVIS DELTAGEREN HAR SAMTYKKET TIL AT VI TAR KONTAKT MED PÅRØRENDE. Deltageren og pårørende kan velge å fylle ut samme dagbok, eller de kan fylle ut digitalt i hvert sitt dokument. Dersom de fyller det ut i hvert sitt dokument gjør det ikke noe om de ikke fyller ut akkurat de samme hendelsene – dette kan vi vi slå sammen når vi legger dataene inn.	<i>Behandler (hvis aktuelt)</i> <ul style="list-style-type: none"> Du sa ja til at vi kan kontakte din behandler. Er dette fremdeles ok? Kan jeg få kontaktinformasjon til behandler? <i>Pårørende (hvis aktuelt)</i> <ul style="list-style-type: none"> Du sa ja til at vi kan kontakte din pårørende. Er dette fremdeles ok? Kan jeg få kontaktinformasjon til pårørende? Pårørende kan gjerne hjelpe deg med å fylle ut dagboken. Dersom digital utfylling: Dere kan velge om dere fyller ut samme dokument, ved å lagre det som en delt fil, eller om dere ønsker å fylle ut hvert deres dokument 	
	Takk igjen for at du vil være med på studien! Jeg sender deg nå dagboken, og tar kontakt med deg om litt igjen for å følge opp og minne deg på å fylle ut dagboken. Husk at du gjerne kan ta kontakt med meg underveis dersom du lurer på noe.	

APPENDIX N: INTERVIEW GUIDE FOR MS PATIENT'S NEXT-OF-KINS

Intervju – pårørende

Målgruppe: pårørende til pasienter som deltar i longitudinell studie. Pasientene intervjues etter at startintervju med pasient er gjennomført. Intervjuet gjennomføres fortrinnsvis over Microsoft Teams, alternativt over telefon.

Informasjon til intervjuer	Script med spørsmål	Notatfelt
Husk å sette på lydopptaker!	<p>Innledning til intervju</p> <p>Takk for at du har takket ja til å delta i studien.</p> <p>For å repetere kort om formålet med prosjektet så omfatter begrepet pasientforløp altså pasientens mange møter og kontaktpunkter med helsevesenet gjennom en sykdomsperiode. I forskningsprosjektet Pathway ønsker vi å utvikle visuelle verktøy som skal gjøre det lettere å forstå og samarbeide om et pasientforløp på tvers av fag og roller i helsetjenesten. Dette også for å kunne kommunisere direkte med pasienter og deres pårørende.</p> <p>Som del av dette, fokuserer vi i studien på <i>pasienters egne erfaringer med pasientforløp</i>, hva slags informasjon man selv mener burde inngå, hvordan informasjonen kan kommuniseres på tvers av tjenesteutøvere med mer. Vi ønsker også å belyse pasientforløpet fra perspektivet til pårørende.</p> <p>Formålet med dette intervjuet er å få vite mer om hvordan du bistår din pårørende gjennom pasientforløpet og hvordan du som pårørende opplever informasjon fra og kommunikasjon med helsetjenesten. I tillegg vil jeg vise deg dagboken, hvordan den fylles ut og hvordan du kan hjelpe med dette.</p> <p>Hvis det er greit for deg starter jeg lydopptaket nå?</p>	

Formål: danne oss et bedre bilde av hvem deltageren er. Ikke behov for å gå i dybden her.	<p>Intro om pårørende</p> <p><i>Bakgrunn (kort)</i></p> <ul style="list-style-type: none"> For å vite litt om hvem du er, lurer jeg på om du først kan fortelle kort om deg og din familie- og jobbsituasjon? 	
Formål: danne oss et bilde av hvordan pårørende har bistått, hvilke møter pårørende har vært med på gjennom prosessen med mer. Danne oss et bedre bilde av pasientforløpet.	<p>Om pårørendes rolle i pasientforløpet</p> <p>Før vi går konkret inn i hva som har skjedd, har jeg noen spørsmål om din rolle som pårørende:</p> <ul style="list-style-type: none"> Hvordan har du som pårørende vært involvert i pasientforløpet så langt? (med på konsultasjoner etc.) Hvordan har dere holdt oversikt over alt? (e.g. notater, dagbok) Pleier du å forberede noe før møter etc.? (e.g. spørsmål) Gjør du noe konkret under/etter møter (forberede spm. i forkant, notater underveis) 	
	<p>Opplevelse av hva som har skjedd?</p> <ul style="list-style-type: none"> Kan du fortelle litt om hva som har skjedd til nå og hvordan du har opplevd det? 	
Formål: få et bilde av pårørendes opplevelse av pasientforløpet, inkludert informasjon fra og kommunikasjon med helsetjenesten.	<p>Opplevelse av kommunikasjon og informasjon</p> <ul style="list-style-type: none"> Føler du at du også blir ivaretatt som pårørende? Får du som pårørende nok informasjon? Hvilke utfordringer ser du fra ditt ståsted? 	

	Instruksjon i bruk av dagbok	
<p>Intervjuer deler skjerm med deltageren slik at de kan se dagboken (dersom intervjuet gjennomføres via Teams). Intervjuer viser deltageren dagboken og forklarer hvordan dagboken er utformet og fylles ut</p> <p>Start med å gå gjennom punktene på side 1 og 2 i dagboken.</p> <p>I sum er vi interessert i at deltageren noterer i dagboken: hva skjedde og når? Hvordan skjedde informasjonen/kommunikasjonen? Hvem tok kontakt med hvem? Hvordan opplevde deltageren dette? Var kommunikasjonen god? Er det informasjon deltageren savner?</p>	<p>Vi vil gjerne at du bistår din pårørende med å fylle ut dagboken.</p> <p>Dere kan selv velge om dere fyller ut det samme dokumentet, eller om dere fyller ut hvert dokument (hvis velger det siste kan vi slå sammen dokumentene til ett sammenhengende dokument).</p> <p>Vi vil at dere fyller ut én rad i skjemaet hver gang</p> <ul style="list-style-type: none"> - Din pårørende er i kontakt med helsetjenesten (konsultasjon, brev, innkalling, telefon, oppmøte, SMS) - Din pårørende har en aktivitet som er relevant for sykdommen (trening, legebesøk, informasjonssøking etc.) - Du fyller ut dato, hvem du er i kontakt med, hvordan kontakten foregikk (e-post, oppmøte etc.) - I tillegg til hva som skjedde, har dagboken et felt der vi ønsker at dere skriver hvordan dere opplevde hendelsen. Det kan inkludere hvordan møtet med og informasjon fra en lege opplevdes, hvordan kommunikasjon mellom ulike deler av helsetjenesten oppleves – eller lignende. <p>Dere kan også gjerne skrive inn sykdomsrelaterte hendelser utover direkte kontakt med helsetjenesten. Som for eksempel egne søk på nett, andre hendelser underveis etc.</p> <p>Generelt er det bedre med for mye enn for lite informasjon: dersom du tror noe er relevant, men ikke er helt sikker, er det bedre at det noteres enn at det ikke noteres.</p>	

	<p>Vi vil gjerne at dagboken fylles ut regelmessig, hver gang det skjer noe, enten det er egne informasjonssøk eller henvendelser fra og møter med helsevesenet.</p> <p>Som vi nevnte i intervju med <navn på pasient / din partner etc.> ønsker vi også at det som har skjedd i pasientforløpet så langt fylles ut. Fra hvordan det startet, til hva som skjedde videre. Det er veldig fint om du har mulighet til å fylle ut hva som har skjedd til nå, og returnere skjemaet til oss via epost når det er fylt ut.</p>	
	<p><i>Oppfølging underveis</i></p> <p>Vi vil gjerne sende deg påminnelser om å fylle ut dagboken og returnere den til oss underveis. Foretrekker påminnelser på SMS/e-post/telefon?</p> <ul style="list-style-type: none"> • Har du noen spørsmål? 	
	<p>Takk igjen for at du takket ja til å delta i studien og tok deg tid til et intervju! Jeg sender deg nå dagboken på e-post, så du også har en versjon.</p> <p>Ta gjerne kontakt med meg underveis dersom du lurer på noe.</p>	

APPENDIX O: START INTERVIEW GUIDE FOR CANCER PATIENTS

Startintervju – pasient

Målgruppe: pasienter som skal delta i longitudinell studie. Pasientene intervjues ved oppstart/inkludering i studien, de inviteres til å føre dagbok, og til et avslutningsintervju. Intervjuet gjennomføres over Microsoft Teams.

Hovedtemaer:

- Innledning til intervju
- Intro om pasient
- Intro om sykdom: Hva har skjedd hittil? Hvordan oppleves kommunikasjonen?
- Pårørende og dokumentasjon
- Instruksjon i bruk av dagbok
- Involvering av pårørende og behandler (der det er aktuelt)

Informasjon til intervjuer	Script med spørsmål	Notatfelt
Husk å sette på lydopptaker!	<p>Innledning til intervju</p> <p>Takk for at du har takket ja til å delta i studien.</p> <p>For å repetere kort om formålet med prosjektet så omfatter begrepet pasientforløp altså pasientens mange møter og kontaktpunkter med helsevesenet gjennom en sykdomsperiode. I forskningsprosjektet Pathway ønsker vi å utvikle visuelle verktøy som skal gjøre det lettere å forstå og samarbeide om et pasientforløp på tvers av fag og roller i helsetjenesten. Dette også for å kunne kommunisere direkte med pasienter og deres pårørende.</p> <p>Som del av dette, fokuserer vi i studien på <i>pasienters egne erfaringer med pasientforløp</i>, hva slags informasjon man selv mener burde inngå, hvordan man ønsker å involveres i eget pasientforløp og hvordan informasjonen kan kommuniseres på tvers av tjenesteutøvere.</p>	

	<p>Formålet med dette første intervjuet er at vi får vite litt om deg og ditt pasientforløp så langt.</p> <p>Hvis det er greit for deg starter jeg lydopptaket nå?</p>	
	<p>Intro om pasient</p>	
Formål: danne oss et bedre bilde av hvem deltageren er. Ikke behov for å gå i dybden her.	<p><i>Bakgrunn (kort)</i></p> <ul style="list-style-type: none"> • Først lurer jeg på om du kan fortelle kort om deg og din familie- og jobbsituasjon? (heltid/deltid/pensjonist). • Hvordan ser hverdagen din ut? 	
	<p>Intro om sykdom: Hva har skjedd hittil? Hvordan oppleves kommunikasjonen?</p>	
Formål: få en oversikt over hva som har skjedd til nå i pasientforløpet.	<p><i>Om sykdom og kartlegging av involverte aktører – behandling og oppfølging:</i></p> <ul style="list-style-type: none"> • Kan du fortelle kort historien om sykdommen din og forløpet så langt? • Hvem har du vært i kontakt med per nå når det gjelder behandling og oppfølging? (fastlege, sykehus, andre tjenester, NAV, pasientorganisasjon, privat osv.). • Har du en kontaktperson eller koordinator? <p><Gå tilbake og ta deltageren gjennom pasientforløp steg for steg, av typen «ok, det begynte sånn og sånn ... du har altså vært i kontakt med fastlege, røntgen ...». «Hvordan opplevde du kontakten?» ...></p>	
	<ul style="list-style-type: none"> • Vet du hva som er videre forløp nå? 	
	<p><i>Kommunikasjon med aktørene i helsetjenesten</i></p>	

	<ul style="list-style-type: none"> Hvordan opplever du kontakten med helsetjenesten? Opplevs det koordinert eller fragmentert? Får du den informasjonen du trenger? 	
	Pårørende og dokumentasjon	
<p>Vi ønsker i utgangspunktet å rekruttere deltagere som har pårørende rundt seg. Dersom det viser seg at deltageren ikke har pårørende rundt seg, bør intervjuer vurdere om deltageren skal med videre.</p> <p>Dersom intervjuer vurderer at deltageren ikke skal bes om å loggføre det videre pasientforløpet, takker vi for intervjuet etter at vi er gjennom intervju spørsmålene og sier at de vil høre tilbake fra oss. Vi må da passe på å ta kontakt senere, takke for at de tok seg tid til intervju og informere om at vi har rekruttert nok deltagere til dagbok eller lignende.</p>	<p><i>Pårørende</i></p> <ul style="list-style-type: none"> Har du pårørende som støtter/bistår deg gjennom behandling og oppfølging? Hvis ja: er pårørende involvert i møtet med helsetjenesten? (er de med på konsultasjoner eller involvert på andre måter) 	
	<p><i>Dokumentasjon av egen sykdom</i></p> <ul style="list-style-type: none"> Noterer du noe om din sykdom, f.eks. en logg eller dagbok? Hvis ja, hvordan (papir, mobil, pc, app? og hvor ofte? 	
	<ul style="list-style-type: none"> Til slutt: Hva er dine forventninger til å være med i studien? 	

<p>Intervjuer deler skjerm med deltageren slik at de kan se dagboken (dersom intervjuet gjennomføres via Teams). Intervjuer viser deltageren dagboken og forklarer hvordan dagboken er utformet og fylles ut</p> <p>Start med å gå gjennom punktene på side 1 og 2 i dagboken.</p> <p>I sum er vi interessert i at deltageren noterer i dagboken: hva skjedde og når? Hvordan skjedde informasjonen/kommunikasjonen? Hvem tok kontakt med hvem? Hvordan opplevde deltageren dette? Var kommunikasjonen god? Er det informasjon deltageren savner?</p> <p>Husk å avklare spørsmål underveis.</p>	<p>Instruksjon i bruk av dagbok</p> <p>Jeg skal nå gå gjennom utfyllingen av dagboken/loggen du skal føre. <forklare eller vise hvordan dagboken ser ut></p> <p>Du skal fylle ut én rad i skjemaet hver gang</p> <ul style="list-style-type: none"> Du er i kontakt med helsetjenesten (konsultasjon, brev, innkalling, telefon, oppmøte, SMS) Du har en aktivitet som er relevant for sykdommen (trening, legebesøk, informasjonssøking etc.) Du fyller ut dato, hvem du er i kontakt med, hvordan kontakten foregikk (e-post, oppmøte etc.) I tillegg til hva som skjedde, har dagboken et felt der vi ønsker at du skriver hvordan du opplevde hendelsen. Dette kan inkludere hvordan du opplevde møtet med og informasjonen fra en lege, i en innkalling eller lignende, eller hvordan du opplever kommunikasjonen mellom ulike deler av helsetjenesten. <p>Du kan også gjærne skrive inn sykdomsrelaterte hendelser utover direkte kontakt med helsetjenesten. Som for eksempel inkludere egne søk på nett, hendelser underveis og hva som evt. gjør at du er fornøyd/mindre fornøyd med informasjonen du sitter på.</p> <p>Husk at eksempelet på hvordan dagboken kan fylles ut, nettopp er et eksempel, og ikke en mal for hvilke formuleringer du må bruke når de skriver dagboken. Du kan f.eks. gjerne skrive mer utfyllende. Det er bedre med for mye enn for lite informasjon: dersom du tror noe er</p>	

	relevant, men ikke er helt sikker, er det bedre at du noterer det i dagboken enn at du ikke noterer det.	
	Vi vil gjerne at du fyller ut dagboken regelmessig . Nå når du får dagboken tilsendt, ønsker vi også gjerne at du fyller inn i dagboken det som har skjedd til nå i pasientforløpet ditt (altså bakover i tid), så godt du klarer/husker. Da kan du gjerne starte med å beskrive hvordan det startet og deretter hva som skjedde videre.	
Dersom deltageren ønsker å fylle ut dagboken på papir (og de ikke ønsker å printe ut selv), sender vi dem dagboken i posten. Husk da å be om postadresse. Dersom deltageren ønsker å fylle ut dagboken digitalt, sender vi dem dagboken på e-post.	<i>Alternativer til utfylling av dagbok</i> <ul style="list-style-type: none"> Hvordan vil du helst fylle ut dagboken, på papir eller på PC? 	
Retur av dagbok til oss: dagboken inneholder nå ikke informasjon om hvordan dagboken returneres til oss. Vi tar sikte på at deltageren returnerer dagboken hver/annen hver uke. Parallelt med at vi følger opp deltageren underveis, kan vi be dem om å returnere dagboken.	<i>Oppfølging underveis</i> <ul style="list-style-type: none"> Vi vil gjerne følge deg opp underveis. Hvordan ønsker du at vi holder kontakt deg underveis med påminnelser og for å høre hvordan det går? (på telefon, SMS, epost) Vi kan tilpasse dette litt underveis, men vi følger deg gjerne opp mer hyppig i perioder hvor det skjer mer, du er i kontakt med helsevesenet, til behandling eller lignende. Du kan gjerne løpende returnere dagboken til oss via e-post. Vi tar kontakt med deg angående retur av dagboken underveis. 	

	<i>Avslutningsintervju</i> Etter 2-4 måneder kontakter vi deg for et avslutningsintervju.	
	<ul style="list-style-type: none"> Har du noen spørsmål? 	
	Involvering av pårørende og behandler (hvis aktuelt)	
KUN RELEVANT HVIS DELTAGEREN HAR SAMTYKKET TIL AT VI TAR KONTAKT MED PÅRØRENDE. Deltageren og pårørende kan velge å fylle ut samme dagbok, eller de kan fylle ut digitalt i hvert sitt dokument. Dersom de fyller det ut i hvert sitt dokument gjør det ikke noe om de ikke fyller ut akkurat de samme hendelsene – dette kan vi vi slå sammen når vi legger dataene inn.	<i>Pårørende (hvis aktuelt)</i> <ul style="list-style-type: none"> Du sa ja til at vi kan kontakte din pårørende. Er dette fremdeles ok? Kan jeg få kontaktinformasjon til pårørende? Pårørende kan gjerne hjelpe deg med å fylle ut dagboken. Dersom digital utfylling: Dere kan velge om dere fyller ut samme dokument, ved å lagre det som en delt fil, eller om dere ønsker å fylle ut hvert deres dokument. 	
	Takk igjen for at du vil være med på studien! Jeg sender deg nå dagboken, og tar kontakt med deg om litt igjen for å følge opp og minne deg på å fylle ut dagboken. Husk at du gjerne kan ta kontakt med meg underveis dersom du lurer på noe.	

APPENDIX P: DEBRIEF INTERVIEW GUIDE FOR MS AND CANCER PATIENTS

Avslutningsintervju – pasient

Målgruppe: Pasienter som har deltatt i longitudinell studie.

Hovedmål: Gjennomgang av dagbok. Sikre, så godt det lar seg gjøre, at alle deler av pasientforløpet er dekket, inkludert hva som skjedde, hvem som initierte kontakten, hvilken kanal kommunikasjonen foregikk via etc. Andre mål: få innsikt i hvordan pasienten vurderer kommunikasjonen underveis i pasientforløpet og hvordan de vurderer samhandling og koordinering på tvers av aktører. Få innsikt i hvordan pasienten har opplevd å være deltager.

Informasjon til intervjuer	Intervjuspørsmål
Husk å sette på lydopptaker!	<p>Innledning til intervju</p> <p>Takk igjen for at du stiller til et avslutningsintervju. Hovedformålet med dette intervjuet er å gå gjennom pasientforløpet ditt steg for steg, slik at vi kan danne oss et så fullstendig bilde som mulig. I tillegg vil vi gjerne høre mer om hvordan du har opplevd informasjons- og kommunikasjonsflyt gjennom pasientforløpet.</p> <p>Jeg vil gjerne ta lydopptak av intervjuet. Hvis det er greit for deg starter jeg lydopptaket nå?</p>
Dette spørsmålet er for å innlede samtalen, og å sørge for at deltageren får luftet ut eventuelle ting de har på hjertet.	<p>Innledningsspørsmål</p> <ul style="list-style-type: none"> Hvordan har det gått siden sist vi snakket sammen?
	<p>Hoveddel: Gjennomgang av dagbok</p>
<p>Mål: Få et så utfyllende bilde av pasientforløpet som mulig.</p> <p>Her tar intervjuer deltageren gjennom alle kontaktpunkter gjennom pasientforløpet. Målet er å utfylle informasjonen vi allerede har og å fange opp informasjon som mangler. For eksempel om påminnelser pasienten har fått underveis eller gjennom hvilken kanal kommunikasjonen foregikk gjennom ved et konkret kontaktpunkt.</p>	<p>Vi skal nå gå gjennom pasientforløpet ditt steg for steg, slik du har beskrevet det i introintervjuet og dagboken. Målet er å få så utfyllende informasjon som mulig om pasientforløpet ditt.</p> <p><start fra begynnelsen og ta deltageren gjennom alle touchpoints vi har notert ned samt evt. manglende informasjon></p> <p>Spørsmål: Hvem initierte kontakten? Hvordan foregikk kommunikasjonen (kanal)? Hvordan opplevde du det? (score) Fikk du påminnelser eller lignende underveis som ikke er notert ned? Er det andre kontaktpunkter du kommer på nå som ikke er notert ned, som er relatert til sykdommen din?</p>
	<p>Når vi nå har gjennomgått og du ser hele pasientforløpet ditt, hva tenker du når du ser hvor mange kontaktpunkter du har?</p>

	Kommunikasjon med aktørene/tjenesten
Mål: få innsikt i hvordan pasienten vurderer kommunikasjonen underveis i pasientforløpet og hvordan de vurderer samhandling og koordinering på tvers av aktører	<p>Så har jeg noen spørsmål om kommunikasjon og informasjonsflyt:</p> <ul style="list-style-type: none"> • Hvordan synes du kommunikasjonen med de ulike aktørene i helsetjenesten har vært? • Hvordan har du opplevd koordinering og informasjonsflyt mellom aktørene i helsetjenesten? (for eksempel mellom fastlege og sykehus) • Har du eksempel på en episode der kommunikasjon-/informasjonsflyt gikk veldig bra? • Har du eksempel på en episode der kommunikasjon-/informasjonsflyt gikk veldig dårlig? • Har du underveis fått presentert noe om ditt pasientforløp, for eksempel i form av et diagram, fremstilling, tabell? • Hva er det egentlig du vil vite om pasientforløpet ditt? I hvilken grad vil du involveres?
	Forbedring
	Hvis du ser for deg nå at alt er mulig teknisk og økonomisk. Hva kunne gjort det lettere for deg som pasient i møtet med helsevesenet?
	Deltagelse i studien
	<p>Utover å få mer kunnskap om pasientforløp, er det også et mål for oss å lære mer om hvordan vi best gjennomfører slike studier. Da er det viktig for oss å vite mer om hvordan det oppleves å være deltager.</p> <ul style="list-style-type: none"> • Hvordan har du opplevd å være deltager i denne studien? • Er det noe du tenker kunne ha vært løst på en måte som var bedre for deg?
	Takk og gavekort
	Da er vi gjennom. Jeg vil gjerne takke deg igjen for at du tok deg tid til å delta i studien. Det er til veldig stor nytte for oss. Alle deltagere får et gavekort som takk for innsatsen. Jeg sender det til deg på epost.

APPENDIX Q: INTERVIEW GUIDE FOR MS PATIENT'S NEXT-OF-KINS

Intervju – pårørende

Målgruppe: pårørende til pasienter som deltar i longitudinell studie. Pasientene intervjues etter at startintervju med pasient er gjennomført. Intervjuet gjennomføres fortrinnsvis over Microsoft Teams, alternativt over telefon.

Informasjon til intervjuer	Script med spørsmål	Notatfelt
Husk å sette på lydopptaker!	<p>Innledning til intervju</p> <p>Takk for at du har takket ja til å delta i studien.</p> <p>For å repetere kort om formålet med prosjektet så omfatter begrepet pasientforløp altså pasientens mange møter og kontaktpunkter med helsevesenet gjennom en sykdomsperiode. I forskningsprosjektet Pathway ønsker vi å utvikle visuelle verktøy som skal gjøre det lettere å forstå og samarbeide om et pasientforløp på tvers av fag og roller i helsetjenesten. Dette også for å kunne kommunisere direkte med pasienter og deres pårørende.</p> <p>Som del av dette, fokuserer vi i studien på <i>pasienters egne erfaringer med pasientforløp</i>, hva slags informasjon man selv mener burde inngå, hvordan informasjonen kan kommuniseres på tvers av tjenesteutøvere med mer. Vi ønsker også å belyse pasientforløpet fra perspektivet til pårørende.</p> <p>Formålet med dette intervjuet er å få vite mer om hvordan du bistår din pårørende gjennom pasientforløpet og hvordan du som pårørende opplever informasjon fra og kommunikasjon med helsetjenesten. I tillegg vil jeg vise deg dagboken, hvordan den fylles ut og hvordan du kan hjelpe med dette.</p> <p>Hvis det er greit for deg starter jeg lydopptaket nå?</p>	

	<p>Intro om pårørende</p> <p><i>Bakgrunn (kort)</i></p> <ul style="list-style-type: none"> For å vite litt om hvem du er, lurer jeg på om du først kan fortelle kort om deg og din familie- og jobbsituasjon? 	
	<p>Om pårørendes rolle i pasientforløpet</p> <p>Før vi går konkret inn i hva som har skjedd, har jeg noen spørsmål om din rolle som pårørende:</p> <ul style="list-style-type: none"> Hvordan har du som pårørende vært involvert i pasientforløpet så langt? (med på konsultasjoner etc.) Hvordan har dere holdt oversikt over alt? (e.g. notater, dagbok) Pleier du å forberede noe før møter etc.? (e.g. spørsmål) Gjør du noe konkret under/etter møter (forberede spm. i forkant, notater underveis) 	
	<p>Opplevelse av hva som har skjedd?</p> <ul style="list-style-type: none"> Kan du fortelle litt om hva som har skjedd til nå og hvordan du har opplevd det? 	
	<p>Opplevelse av kommunikasjon og informasjon</p> <ul style="list-style-type: none"> Føler du at du også blir ivaretatt som pårørende? Får du som pårørende nok informasjon? Hvilke utfordringer ser du fra ditt ståsted? 	
Formål: danne oss et bedre bilde av hvem deltageren er. Ikke behov for å gå i dybden her.		
Formål: danne oss et bilde av hvordan pårørende har bistått, hvilke møter pårørende har vært med på gjennom prosessen med mer. Danne oss et bedre bilde av pasientforløpet.		
Formål: få et bilde av pårørendes opplevelse av pasientforløpet, inkludert informasjon fra og kommunikasjon med helsetjenesten.		

	Instruksjon i bruk av dagbok	
<p>Intervjuer deler skjerm med deltageren slik at de kan se dagboken (dersom intervjuet gjennomføres via Teams). Intervjuer viser deltageren dagboken og forklarer hvordan dagboken er utformet og fylles ut</p> <p>Start med å gå gjennom punktene på side 1 og 2 i dagboken.</p> <p>I sum er vi interessert i at deltageren noterer i dagboken: hva skjedde og når? Hvordan skjedde informasjonen/kommunikasjonen? Hvem tok kontakt med hvem? Hvordan opplevde deltageren dette? Var kommunikasjonen god? Er det informasjon deltageren savner?</p>	<p>Vi vil gjerne at du bistår din pårørende med å fylle ut dagboken.</p> <p>Dere kan selv velge om dere fyller ut det samme dokumentet, eller om dere fyller ut hvert dokument (hvis velger det siste kan vi slå sammen dokumentene til ett sammenhengende dokument).</p> <p>Vi vil at dere fyller ut én rad i skjemaet hver gang</p> <ul style="list-style-type: none"> - Din pårørende er i kontakt med helsetjenesten (konsultasjon, brev, innkalling, telefon, oppmøte, SMS) - Din pårørende har en aktivitet som er relevant for sykdommen (trening, legebesøk, informasjonssøking etc.) - Du fyller ut dato, hvem du er i kontakt med, hvordan kontakten foregikk (e-post, oppmøte etc.) - I tillegg til hva som skjedde, har dagboken et felt der vi ønsker at dere skriver hvordan dere opplevde hendelsen. Det kan inkludere hvordan møtet med og informasjon fra en lege opplevdes, hvordan kommunikasjon mellom ulike deler av helsetjenesten oppleves – eller lignende. <p>Dere kan også gjerne skrive inn sykdomsrelaterte hendelser utover direkte kontakt med helsetjenesten. Som for eksempel egne søk på nett, andre hendelser underveis etc.</p> <p>Generelt er det bedre med for mye enn for lite informasjon: dersom du tror noe er relevant, men ikke er helt sikker, er det bedre at det noteres enn at det ikke noteres.</p>	

	<p>Vi vil gjerne at dagboken fylles ut regelmessig, hver gang det skjer noe, enten det er egne informasjonssøk eller henvendelser fra og møter med helsevesenet.</p> <p>Som vi nevnte i intervju med <navn på pasient / din partner etc.> ønsker vi også at det som har skjedd i pasientforløpet så langt fylles ut. Fra hvordan det startet, til hva som skjedde videre. Det er veldig fint om du har mulighet til å fylle ut hva som har skjedd til nå, og returnere skjemaet til oss via epost når det er fylt ut.</p>	
	<p><i>Oppfølging underveis</i></p> <p>Vi vil gjerne sende deg påminnelser om å fylle ut dagboken og returnere den til oss underveis. Foretrekker påminnelser på SMS/e-post/telefon?</p>	
	<ul style="list-style-type: none"> • Har du noen spørsmål? 	
	<p>Takk igjen for at du takket ja til å delta i studien og tok deg tid til et intervju! Jeg sender deg nå dagboken på e-post, så du også har en versjon.</p> <p>Ta gjerne kontakt med meg underveis dersom du lurer på noe.</p>	

APPENDIX R: INTERVIEW GUIDES FOR PATIENT'S TREATING PHYSICIANS



Intervjuguide

Intervju - behandler

Målgruppe: Behandler til en pasient som deltar i longitudinell studie (etter samtykke fra pasienten, som også har formidlet kontakt med behandleren). Formål: Oversikt over pasientforløpet og helsetjenestens kontakt med pasienten, sett fra beholders perspektiv.

Informasjon til intervjuer	Intervjuspørsmål
	<p>Innledning</p> <p>Takk for at du tar deg tid til å stille til et intervju.</p> <p>Formålet med dette intervjuet er å få vite mer om pasientforløp, sett fra ditt perspektiv i rollen som behandler. Vi vil vite mer om hvordan kommunikasjon og informasjon fra helsetjenesten til pasienten og mellom ulike deler av helsetjenesten foregår, sett fra ditt perspektiv som behandler. Vi vil også gjerne vite mer om hvilke behov og ønsker du har, og hvordan man best kan ta hensyn til ditt perspektiv i utvikling av nye verktøy for å administrere og koordinere pasientforløp.</p> <p>Før vi begynner, har du noen spørsmål angående studien og/eller intervjuet?</p> <p>Jeg vil gjerne ta lydopptak av intervjuet. Om det er i orden for deg setter jeg nå på lydopptakeren? <sett på lydopptaker></p>
	<p>Pasientforløp</p> <p>Nå skal vi snakke om ditt møte med NN som vi allerede har hatt et intervju med. NN har selv sagt godkjent at du fritas fra din taushetsplikt. <vis dokumentasjon på dette>.</p> <ul style="list-style-type: none"> • Hvordan har du i din rolle som lege vært involvert i NNs pasientforløp? (beskriv gjerne steg for steg gjennom forløpet, inkludert hvilke andre aktører du er i kontakt med) • Hvilke aktører er involvert i NN sin behandling? • Hvor ofte ser du NN og hvor lenge varer møtet deres? • Hvilke datasystemer bruker du for å følge opp pasienten? • Hvilke eksterne systemer/databaser har informasjon om pasienten?
	<p>Kommunikasjon og samhandling med andre aktører</p> <ul style="list-style-type: none"> • Hvilke andre aktører kommuniserer du med om pasienten, både internt og eksternt? • Hvilken informasjon har du IKKE tilgang til hos de andre aktørene? • Er det noe informasjon som ville vært nyttig for deg å ha?
	<p>Informasjon om pasientforløpet til NN</p> <ul style="list-style-type: none"> • Hva er det viktig for deg å vite om NN mellom de gangene dere møtes?

	<ul style="list-style-type: none">• Ville det vært nyttig for deg og hatt en oversikt over pasientforløpet fram til nå?• Hvilken informasjon burde inngått i denne oversikten?• I så fall hvordan bør den informasjonen organiseres – visuelt, tabell, diagram?
	Til slutt om ønsker og fremtidsutsikter <ul style="list-style-type: none">• Er det noe du savner for å kommunisere med kolleger om pasientforløpet?• Er det noe du savner for å kommunisere med pasienter om pasientforløpet?
	Takk for at du tok deg tid til et intervju!

APPENDIX S: DIARY FOR CANCER PATIENTS

Ha dette skjemaet lett
tilgjengelig og fyll ut
fortløpende!

Strukturert dagbok



Fyll ut én rad i skjemaet hver gang ..

- du er i kontakt med helsetjenesten (f.eks. konsultasjon, brev, innkalling, telefon, oppmøte, SMS)
- du har en aktivitet som er relevant for sykdommen (trening, legebesøk, informasjonssøking, digitalt hjelpemiddel)
- Alt du synes er relevant kan du loggføre (bedre med for mye enn for lite)



Vi holder kontakt underveis ...

- .. for å høre siste nytt
- .. for å avtale neste steg



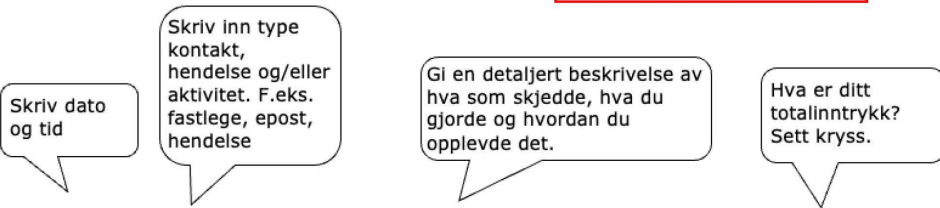
Til sist ringer vi deg for et avslutningsintervju ..

- .. der vi går gjennom dagboken din
- Deretter sender vi deg gavekort

Takk for at du hjelper oss.
Ditt bidrag er viktig for vår
forskning! Ta kontakt hvis du
lurer på noe.











Anna Grøndahl Larsen
Mobil: 977 23 526
e-post: anna.g.larsen@sintef.no

Eksempel



Dato og tid	Kontakt Aktør Hendelse	HVA SKJEDDE? OPPLEVELSE OG FORVENTNING? FORSLAG TIL FORBEDRING?	Kryss av
Juni/juli		(beskriv hvordan det startet, mistanke, symptom osv.)	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
13.aug kl. 13:30	Kontaktet fastlege, telefon	Snakket med ... Fikk time raskt ...	<input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
14. sept. Kveld	Hendelse Egne tanker Etc.	Denne dagen var spesiell fordi ... Jeg opplevde det som ... Dette hadde vært fint hvis ... Jeg savner informasjon om ...	<input type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
27. sept. kl.13:35	Web	Jeg gikk inn på <nettsted> for å sjekke Dette viste seg å være noe helt annet enn jeg fikk beskjed om av ... Jeg foreslår at dere ...	<input type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
5. nov kl. 09:30	Konsultasjon	Jeg møtte opp på ... Jeg opplevde kommunikasjonen med legen som ... Jeg skulle ønske at jeg fikk vite mer om ...	<input type="checkbox"/> <input type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Start å fylle ut på denne siden

Dato og tid	Kontakt Aktør Hendelse	HVA SKJEDDE? OPPLEVELSE OG FORVENTNING? FORSLAG TIL FORBEDRING?	Kryss av
			<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>     
			<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>     
			<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>  