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Supporting Integrated Care through Visualization of Shared Medical Documents and Communication

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Dedication

I dedicate this modest work to

My dear father. No dedication can express my love, respect, and admiration for you. You have been a source of tenderness, love, and encouragement that has helped me evolve into the young woman I am today.

To my dear mother, the symbol of dedication and kindness, no dedication could ever be eloquent enough to express what you truly deserve for all the sacrifices you have made for me since my birth, during my childhood, and even now in my adulthood.

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To my husband Abdelfettah and my princess Aya Qudes who were the source of my energy through this Ph.D. journey.

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Abstract

The demand for inter-organizational cooperative (IOC) problem-solving is increasing. CSCW studies advocated the centrality of awareness to foster this cooperation. Yet, stakeholders and data fragmentation impede gaining this awareness. Studies suggested that furnishing stakeholders with overview displays helps them comprehend dispersed activities and align their work. However, in IOC, stakeholders come from diverse backgrounds and have different practices, and information needs, making a stable presentation ineffective. To address this, we adopted a practice-centered computing approach to investigate the practices allowing achieving an overview to inform the design of technological solutions. Therefore, we conducted a case study focusing on achieving an overview of a patient's case within an integrated care context. Results showed that overview is: 1) a dynamic, individualist process, 2) based on shared documents and communication, and 3) used differently according to the situation. Based on those results, we defined design implications to support achieving an overview in IOC and translated them into a model called CaseOverview. The evaluation showed that systems should allow a shift from comprehensive to situated overviews, offer problem-based overviews, and support temporal and social awareness. This work contributes to the CSCW and health informatics communities by participating in the ongoing discussion on overviews and emphasizing the need to consider a practice-centered approach and the significant role of documents in visualizing overviews.

Keywords: Inter-organizational cooperation, Visualization, Integrated care, CSCW, Medical informatics

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List of abbreviations

ANS Agence du Numérique en Santé

ARS Agence Régionale de Santé

CGTS Centre de Gestion des Terminologies de Santé

CLIC Centre Locaux d'Information et de Coordination

CPS Cartes de Professionnels de Santé

CPTS Communauté professionnelle territoriale de santé

CSCW Computer-Supported Cooperative Work

DNS La délégation ministérielle du numérique en santé

EDMS Electronic Document Management System

EHR Electronic Health Record

EMR Electronic Medical Record

ESP Equipe de Soin Primaire

GHT Groupement Hospitalier de Territoire

GRADs Groupement Régional d'Appui au Développement de la e-Santé

IC Integrated C

IOC Inter-organizational cooperation

INS Identifiant National de Santé

MSP Maison de Santé Pluridisciplinaire

MAIA Méthode d'Action pour l'Intégration des services d'aide et de soins dans le champ de l'Autonomie

PAERPA Personnes Agées en Risque de Perte d'Autonomie

POMR Problem-Oriented Medical Record

PTA Plateformes territoriales d'appui

SOAP Subjective, Objectives, Assessments, and Plans

SMT Serveur Multi-Terminologies

Chapter 1: Introduction

In tightly connected dynamic environments such as healthcare, engineering, and crisis management, inter-organizational cooperation (IOC) between stakeholders from different disciplines and organizations is crucial to ensure the activity's success (Hocevar et al., 2011; Mervyn et al., 2019). Yet, within this context, where the spectrum of collective work crosses the organizations' boundaries, many challenges hinder achieving joint actions. Firstly, the dispersion of the cooperating actors across different organizations results in the fragmentation of information generated by work activities supported by siloed systems (Roy et al., 2017; Svensson, 2019; Williams & Sullivan, 2009). Secondly, each organization has its aims, roles definitions, and work processes, which makes it difficult to be aware of the work of the other actors engaged in joint actions and activities (Hocevar et al., 2011; Saoutal et al., 2015; Stoll et al., 2010). Actors in these contexts, therefore, rely on their individual abilities to gather and exchange information to stay informed of events, track the progress of the collective efforts, and act accordingly (Treurniet & Wolbers, 2021). In those information-intensive environments, collecting and aggregating information from various sources is challenging (Jensen & Bossen, 2016).

Many research work that has been conducted to tackle these challenges promotes the creation of visualization systems that allow stakeholders to get an **overview** of what has been done, showing the information that is necessary to pursue their lines of action heedfully (Frost & Gabrielli, 2013; Fu et al., 2022; Hertzum, 2017). Existing work has shown that visualizations that allow getting an overview help the actors to discover the perimeter of their task and who is involved in these tasks because it helps understand who performs what, when, who is affected, and who should be notified of any new move (Bjerknes & Kautz, 1991).

The concept of an "overview" is commonly used in research on information visualization. However, there is little agreement on its meaning and how it relates to the understanding of a situation and to the navigation in information spaces, presenting the technologically supported repository of organizational information that is established and sustained by multiple stakeholders to support their cooperative work (Schmidt & Bannon, 1992). In their work, (Hornbæk & Hertzum, 2011) highlighted that the literature describes at least two meanings of the term "overview." First, some authors use it to refer to data user-interface components. In this sense, overviews are constructed from a collection of objects of interest and represent them (Greene et al., 2000). Other authors use the term "overviews" to refer to the users' process of gaining a broad understanding of their information space, which they call "overviewing." For example, (Spence, 2007) suggested that an overview allows a quick and effortless awareness of one aspect, for instance, the last changes that have been done in an information space. Therefore, (Hornbæk & Hertzum, 2011) have formulated a model that integrates the most significant aspects from multiple studies using the notion of overview into a cohesive classification system.

> *"Overview is an awareness of [an aspect] of an information space, acquired by [a process] [at a time], useful for [a task] with [an outcome], and provided by [viewtransformed] [visualization]."* (Hornbæk & Hertzum, 2011, p. 4)

One way to deal with supporting overviews is to adopt a data-oriented perspective, meaning that to create an overview, systems should aggregate and organize data (Fu et al., 2022; Lasko et al., 2020). However, stakeholders come from different backgrounds and specialties within inter-organizational cooperation and have different practices (Lasko et al., 2020). Therefore, while centralized systems support data aggregation from different systems, they must integrate the

practices and fulfill the various needs (Bardram & Houben, 2018; Fu et al., 2022; Lasko et al., 2020). Indeed, whilst stakeholders are surrounded by an abundance of information that aids in their comprehension of the broader situation, they tend to prioritize attaining a situated awareness. This situated awareness centers upon the most pertinent element that pertains to the current context, i.e., The motivation behind their effort to attain awareness pertains to the current situation (Blomberg & Karasti, 2013). Moreover, the data stored within those integrated and standardized systems come from various sources and are semantically related to the specialties of their authors (Mønsted, 2015; Vos et al., 2020). Therefore, stakeholders struggle to use this data, as the integration may lead to a loss of meaning (Bjørnstad et al., 2017; Vos et al., 2020; Zhang et al., 2017).

Thus, other research on achieving an overview has identified the importance of stakeholder interactions and sense-making (Bossen & Jensen, 2014; Hertzum, 2017). Those studies highlight that investigating the practices that underlie the creation of an overview is imperative. The authors argue that overview cannot be viewed as a separate and distinct activity but is intertwined with the purpose it serves. Therefore, understanding how an overview is constructed is fundamental to comprehending its usefulness in achieving specific goals (Hornbæk & Hertzum, 2011). Subsequently, comprehending and facilitating the active endeavor to establish and uphold an overview to bolster awareness present significant challenges for the future of visualization systems (Hornbæk & Hertzum, 2011).

In our research work, we have adopted the second perspective. We claim that considering the work practices of the various stakeholders may lead to designing visualization systems that foster the creation of situated overviews that support situated awareness in IOC. Therefore, we anchor our research in the practice-centered computing (Schmidt, 2018) tradition to explore how to design visualization systems that foster achieving an overview from understanding the IOC practices.

The case we have worked on is in the healthcare domain, and more precisely, the integrated care situation.

In fact, as the prevalence of multimorbidity rises, patients require care from a diverse group of specialized and non-specialized care actors, who generally work across different settings and cooperate within complex and extensive illness trajectories (Mønsted et al., 2011). Consequently, to coordinate their efforts and establish cohesive protocols for guiding patients through the healthcare system, governmental authorities have facilitated the development of integrated care (IC) programs (Kodner & Spreeuwenberg, 2002). One of the salient goals of IC is to provide patient-centered, holistic, and integrative care that aligns with the patient's needs and responds to their health goals by managing the different levels of responsibilities between the different actors varying between medical and social actors, as well as the patient's informal caregivers (Tian et al., 2022). However, while integration is proclaimed as the goal and the best way to improve the healthcare system, its application is complex (Armitage et al., 2009). This complexity is related to the intricacy of healthcare activities (Platt et al., 2019), the heterogeneity of perspectives, goals, values, and expectations (Gagliardi et al., 2008), the gap between the goals of policymakers and the ones of care actors (S. Martin, 2010) and the geographical distance and distribution of the care actors (Svensson, 2019)

Furthermore, this distribution causes the fragmentation of data and information issued by the different care actors engaged in the patient's treatments, which increases the efforts needed to construct the overview of a patient's case, which is necessary to coordinate the medical activities and to ensure their coherence (Svensson, 2019). This overview is defined as *"how healthcare professionals arrive at a sufficiently informed, accountable, and coherent understanding of a*

situation so that they are capable of acting consciously and with confidence" (Bossen & Jensen, 2014, p. 1).

Indeed, various studies argued that the one essential component to ensure the success of IC is maintaining a solid information awareness among the care actors, as it fosters inter-group cooperation and eases handovers (Cabitza et al., 2011). Moreover, ensuring the transmission of the correct information at the right moment contributes to integrating the appropriate care services (Protti, 2009) and alleviates the decision-making process (Steele Gray et al., 2021).

To overcome the challenges that hinder achieving overview, many initiatives were launched to create nationwide Electronic Health Records as standardized and centralized solutions permitting access to patients related data and information and allowing overview building (Cresswell, Worth, et al., 2012).

However, the archival-based approach to feeding those systems has been criticized, raising the that Electronic Health Records (nationwide EHRs) documentation generally serves administrative activities rather than medical ones (Adamson et al., 2020; Cresswell, Robertson, et al., 2012). Moreover, numerous investigations have highlighted the incompleteness and obsoleteness of national health records (Shah & Khan, 2020). Then, when systems are fed with patients' information, they tend to encompass information overload, which poses significant readability challenges (Amir et al., 2015). Furthermore, a substantial portion of their content depends on the context in which it has been collected (Zhang et al., 2017), rendering them vulnerable to loss of meaning during transmission across various settings.

Accordingly, to ease the readability and the navigation through the different contents of an EHR to get a patient's case overview, visualization systems were proposed to spot the progress of the various vital values and events (Rind et al., 2013). However, those overview systems focused on aggregating and displaying the information without considering the clinical work practices (Fu et al., 2022). First, those systems present information uniformly to all healthcare professionals involved in the patient's care, disregarding the variations in their information requirements (Jensen & Bossen, 2016). Second, their emphasis lies on presenting structured data while neglecting the significance of showcasing unstructured document-based information, which is a pivotal element in medical coordination activities (Farri et al., 2012; Mendes & Almeida, 2020). Indeed, documents enable care actors to obtain critical information about the different stages of a patient's case (Mønsted et al., 2011; Sultanum, Brudno, et al., 2018), and they answer questions that may arise during various care episodes. Documents also serve the legal side of medical work as they remain as unaltered facts, unlike structured data that changes over time with the progress of the patient's case, thus safeguarding the patient's medical history (Lovis et al., 2000).

In France, the healthcare system encompasses fragmented public and private sectors. The French government launched a National Strategic Plan 2018-2022 to promote the integration of the healthcare systems and the cooperation among its stakeholders to deliver quality care services. In parallel, the French government launched the population-based approach trial, which aims at defining integrated care pathways for dedicated pathologies, aiming for better health at a better cost. Then, to enhance the communication and information sharing within these care pathways, the French government is promoting, alongside the Regional Health agencies, the use of a new standardized system called "e-parcours."

Following a practice-centered computing approach, this thesis aims (1) to investigate the existing IC practices to build and use a patient's case overview; (2) to inform the design of an overview visualization to support cooperation across organizational boundaries. Accordingly, we conducted a case study in Aube County (N-E France). This research was part of a doctoral project

that received funding from Aube County and the Grand East Region. Its objective was to define a design framework for information systems that support new health organization models. We were able to access fieldwork through a research partnership between the university and the Hospital Group of Champagne Sud (GHT), which is involved in a pilot study to implement a population-based approach in the region. Through this partnership, we were able to recruit care actors who were involved in the first phases of testing the population-based approach. Their interest in this new cooperative approach to managing patients made them suitable candidates for our research focus.

We have investigated the practices of care actors working within this context by conducting fieldwork and using qualitative research methods following three steps.

1) **An empirical study** investigating cooperative practices permitting care actors to construct an overview across boundaries. We interviewed care actors from various practices and sectors between January and October 2021. During the interviews, we had the opportunity to observe the work environment and the various tools used by the care actors to gain and sustain knowledge about the patient's case. Unfortunately, the care actors were reluctant to permit us to take pictures of the documents and tools due to the presence of medical information. As a result, we only had the corpus of the recorded interviews with the care actors. The analysis of the data collected during this step revealed the central role of the shared medical documents as the building blocks of the case overview and the essential role of communication as a facilitator to contextualize and enhance the understanding of the content shared within the documents. The analysis also pinpointed challenges related to the identification of the other care actors working around the patients and the issues faced during the exchange and the reception of the medical documents

2) **Design implications** were derived from the results of the first step. These design implications were put together in a model that we have called CaseOverview.

3) **Scenario-based evaluation of CaseOverview.** We designed mock-ups illustrating the model using Figma[1] and conducted a scenario-based evaluation workshop and a series of interviews in February 2023 to collect care actors' feedback on the model.

Our work contributes to the ongoing discussion about enhancing inter-organizational cooperation through the support of an overview to achieve awareness, which is central to cooperative practices. We also contribute to health informatics research by addressing the challenges of visualizing and navigating medical information to promote cooperation within integrated care contexts.

[1] https://www.figma.com/

Thesis Structure

The rest of this manuscript is structured as follows:

Chapter 2 (State of the art) presents the role of overview in cooperation. We then focus on the integrated care context. Therefore, we describe the context and the role of clinical overview and medical data in medical activities. We then review the literature on Electronic Health Records to highlight the way they support overview in IC. Afterward, we detail their limits.

Chapter 3 (Case Study) starts by presenting the French context, highlighting the efforts made by several governments to integrate the healthcare system through various policies, organizational, and technological solutions. We then focus on the situation in Aube County. We then depict our fieldwork in this county, presenting the methods to collect and analyze the data. We then present the results of the qualitative analysis performed on the collected empirical material.

Chapter 4 (Design of CaseOverview model) starts by depicting the design implications resulting from the qualitative analysis of the data collected during the fieldwork in a model. Then, we present the mock-up built through a scenario-based approach. These mock-ups, therefore, translate the design implications into a tangible system.

Chapter 5 (Evaluation) describes the first assessment of the CaseOverview mock-up during a scenario-based evaluation workshop followed by a set of interviews.

Chapter 6 (conclusion and perspective) summarizes the work of the present research, discusses the contributions, and presents research perspectives.

Chapter 2: State of the Art

To support the creation of an overview within an inter-organizational context, we must first understand what an overview is, how it is used, and what role does it play for cooperative practices. After reviewing the concept of overview in general, we then focus on overview in the context of integrated care, which we describe accordingly. We finally review the literature that investigates the technological solutions offered for integrating medical data, ensuring systems interoperability, and fostering the creation of an overview through medical visualization solutions.

2.1 Overview and Cooperation

Data within organizations are documented in different formats and through various shared and personal artifacts (Muller, 2008; Persson et al., 2016). This fragmentation hinders cooperation among stakeholders working within those organizations. Finding adequate, up-to-date data to develop and maintain awareness of the different situations becomes more complicated if the stakeholders belong to different organizations (Persson et al., 2016; Sarshar et al., 2016; Treurniet & Wolbers, 2021). Therefore, in some situations, the involved stakeholders need to get an overview of the situation to be able to coordinate their activities (Bardram & Houben, 2018; Gustavsson et al., 2022; Vos et al., 2020).

The concept of an "overview" is commonly used in information visualization research and practice, even if its meaning can differ. Indeed, (Hornbæk & Hertzum, 2011) noted that the term "overview" has at least two meanings in literature. One is technologically focused and understands overviews as constructed from a collection of objects of interest and represents them (Greene et al., 2000). Other authors use the term "overview" to refer to the users' process of gaining a broad understanding of the information space, which they call "overviewing."

In the first perspective, systems creating an overview should aggregate and organize data to offer structured, insightful visualization (Fu et al., 2022; Lasko et al., 2020).Those overview visualizations are defined as “an interactive visualization that shrinks an information space of data to a coarse level of granularity to provide visual summarizations of content, structure, or dynamics of the data while keeping the capability of showing more details through user interactions” (Liu, 2019). The second perspective acknowledges that achieving an overview relates to stakeholders’ activity and interactions to make sense of the data they possess (Bossen & Jensen, 2014; Hertzum, 2017). In line with this view, (Hornbæk & Hertzum, 2011) proposed a model that defines overview as the **need to be aware of something**. This model outlines the different aspects of an overview, including how it is obtained, when it is obtained, and the benefits it can offer. Figure 1 illustrates the different components that make up this overview.

> *"Overview is an awareness of [an aspect] of an information space, acquired by [a process] [at a time], useful for [a task] with [an outcome], and provided by a [view transformed] [visualization]."* (Hornbæk & Hertzum, 2011, p. 2)

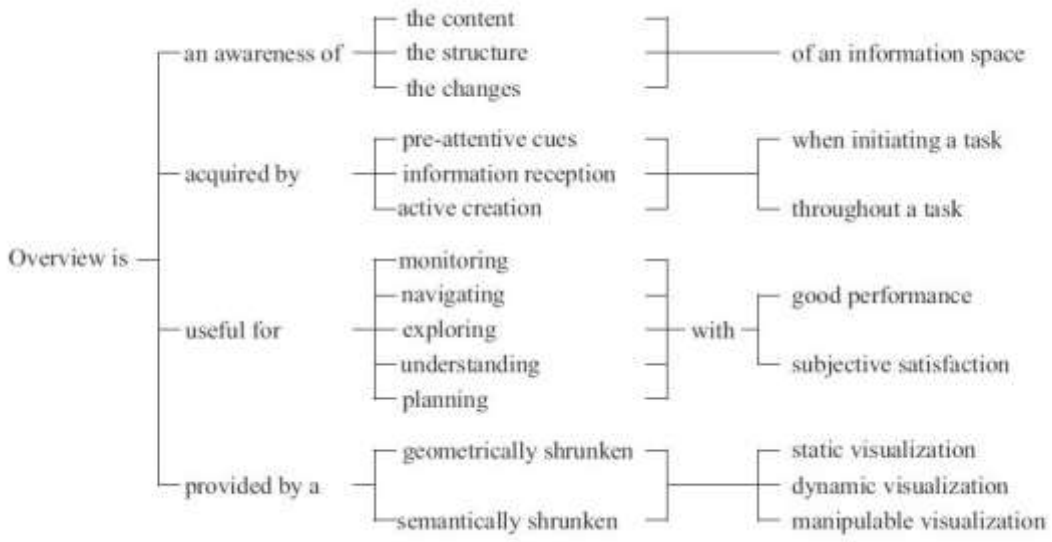


Figure 1 Taxonomic model of overview (Hornbæk & Hertzum, 2011)

Indeed, a compelling overview can act as a facilitator that "*provides users with an immediate appreciation for the size and extent of the collection of objects the overview represents, how objects in the collection relate to each other, and, importantly, what kinds of objects are not in the collection*" (Greene et al., 2000). Accordingly, this overview will support activities ranging from planning, decision-making, and better coordination (Bjerknes & Kautz, 1991; Bossen & Jensen, 2014; Cushing et al., 2006; Gustavsson et al., 2022). Then, the characteristics of the overview visualization (for instance, the approaches for shrinking the information space of data or the techniques for interaction and details representation) will change according to the role aimed for by the projected overview (Liu, 2019). For example, monitoring the information space and providing trends and anomalies imbue the overview visualization with characteristics akin to those of a decisional dashboard.

From a CSCW perspective, an overview can be considered as an instance of situation awareness (Bossen & Jensen, 2014; Hornbæk & Hertzum, 2011) that is defined by (Endsley, 1995) as*: "the perception of the elements in the environment within a volume of time and space, the comprehension of their meaning, and the projection of their status in the near future."* Moreover, by identifying how an overview is achieved, (Bossen & Jensen, 2014) found similarities between the overview types to achieve and the other kinds of awareness. For instance, acquiring a historical overview corresponds to getting temporal awareness.

Regardless of its type, an overview is essential in comprehending the various cooperative activities (Bertelsen & Bødker, 2001). Therefore, it is regarded as one of the critical dimensions to consider when creating common artifacts (Robinson, 1993), as it gives the cooperating actors sufficient information about their activities and how they relate to each other.

However, creating these common artifacts that allow achieving an overview in the IOC context is challenging. Firstly, the compartmentalization between the various organizations participating in the joint action hinders data sharing. Thus, stakeholders lack insights into their cooperators' activities as the shared data tends to be incomplete or absent (Bossen & Grönvall, 2015). Furthermore, while technology can overcome fragmentation challenges by offering an overview by gathering data from different sources, achieving an overview cannot be reduced to accessing distributed data (Treurniet & Wolbers, 2021). Moreover, In IOC, stakeholders from various backgrounds and specialties document their work according to their specialties and have specific

needs in terms of data to fulfill their tasks (Vos et al., 2020). CSCW literature stressed that the overview needed by each actor evolves according to the evolving situations (Bertelsen & Bødker, 2001; Jensen & Bossen, 2016). Therefore, offering visualizations that do not respond to the various need or evolve according to the case's evolution will limit the stakeholders' effort to achieve the optimal overview needed to fulfill their activities (Fu et al., 2022; Lasko et al., 2020). Indeed, a simple visualization of all the physical measurements over a period does not grant achieving an overview, as interaction with other collaborators and data space is needed (Bertelsen & Bødker, 2001; Bossen & Jensen, 2014; Hertzum & Simonsen, 2015). While visualizations generally give insightful presentations of data that aim to permit building an overview, (Hertzum & Simonsen, 2015) pinpointed that the details helping to extend the overview are conveyed through the interaction between the collaborating actors.

Therefore, (Hornbæk & Hertzum, 2011) reported the need to understand how an overview is created, maintained, and adjusted according to the various situations in order to be able to support it technologically.

2.2 Integrated Care

The growing incidence of multimorbidity has led to the involvement of diverse specialized and non-specialized care actors, who may operate within distinct organizational structures and collaborate across multiple extended illness pathways (Mønsted et al., 2011). This care delivery approach is called integrated care (Kodner & Spreeuwenberg, 2002).

> *"Care resulting from a practice team of primary care and behavioral health clinicians, working together . . . [in] a systematic and cost-effective approach to provide patient-centered care for a defined population"* (Peek & National Integration Academy Council, 2013)

Integrated care (IC) is also known as managed care in the US, shared care in the UK, transmural care in the Netherlands, or comprehensive care and disease management. The literature reveals multiple definitions according to the different stakeholders involved in integrated care (e.g., clinical vs. managerial). (Goodwin, 2016) grouped the most used definitions according to the healthcare system perspective, the manager's perspective, the social science perspective, and the patient's perspective. From those definitions, Goodwin spotted two principal characteristics of integrated care; first, integrated care brings together the fragmented parties participating in designing and delivering the care services to create a "whole." Second, the created whole must ensure adequate treatment for the patient (Goodwin, 2016).

One of the primary objectives of Integrated Care (IC) is to offer patient-centered, comprehensive, and integrated healthcare that corresponds to the patient's requirements and meets their health objectives. This is accomplished by effectively managing the diverse responsibilities among the various stakeholders, including medical and social actors, as well as the informal caregivers of the patient (Tian et al., 2022). To attain those goals, different types of integration are proposed (Lewis et al., 2010), from full organizational integration, administrative and back-office integration, clinical services integration, policies and norms integration, or systematic integration, which intends to ensure consistency of all the rules through all the organizations. Then, the intensity of integration between the various entities hinges on the severity of the patient's situation, goals, and needs (Leutz, 1999). For instance, an elderly patient with complex, uncompromising conditions mandates full organizational integration. Thereafter, the different types of integrations are applied to different scopes to fulfill their goals, which create different forms of integrated care (Leutz, 1999):

- ***Horizontal integration*** groups the different health and social services as well as the various care actors to form multi-disciplinary teams and care networks.
- ***Vertical integration*** joins primary, community, hospital, and tertiary care services. The integrated care pathways surface as a protocol within this form of integrated care to create treatment plans for patients suffering from specific diseases (such as heart failure or diabetes) by defining the roles and the different transitions between the various integrated services.
- ***The sectoral integration*** that emerges within the boundaries of one sector (e.g., merging between horizontal and vertical integration to ensure mental health services);
- ***People-centered integration*** joins patients and providers to enroll the patient in the decision-making process.
- ***Whole-system integration***: that covers public health by adopting population-based and patient-centered approaches.

Even with the widespread endorsement of integration as the most effective strategy for enhancing the healthcare system, its implementation remains complicated (Armitage et al., 2009). The complexity of enacting integrated care is directly linked to the intricacy of healthcare activities, mainly when care is provided to patients with co-morbid conditions. Such illnesses are often chronic, unpredictable, and incurable (Platt et al., 2019), thereby making it challenging to cater to the continuous needs of patients, who may require various care services that may be offered consecutively or simultaneously by different care actors (Kodner & Spreeuwenberg, 2002).

Moreover, while the definition of integrated care reflects the need to join work done by the differently engaged stakeholders, creating a shared understanding and goals is rugged (Wildridge et al., 2004). This difficulty arises from the need to bring together perspectives from stakeholders with different roles, values, expectations, and power, which can hinder the success of integrated care programs (Gagliardi et al., 2008). This challenge is exemplified by the findings of (S. Martin, 2010), which highlight the divergence between the goals of policymakers and general practitioners. While policymakers tend to focus on the impact of integrated care on organizations, general practitioners struggle to align with population-level objectives and tend to adopt individualistic practices. Moreover, (Williams & Sullivan, 2009) asserted that the lack of training and support for care actors attempting to cooperate to attain joint action contributes to this gap between strategy and implementation. Furthermore, compartmentalizing the different settings and actors providing the care service adds another layer of complexity (Glendinning, 2002; Williams & Sullivan, 2009). Subsequently, this compartmentalization leads to the fragmentation of medical data across care actors, which then requires extra effort to construct the patient's overview needed to coordinate medical activities and ensure their coherence and continuity (Svensson, 2019).

Prior research has emphasized the imperative of establishing strong interrelationships, promoting various levels of trust, and fostering cooperation and communication among care actors to surmount the diverse obstacles impeding the success of IC (Browne et al., 2007; Kodner & Spreeuwenberg, 2002; Williams & Sullivan, 2009). In addition, it is imperative to uphold robust data awareness amongst care actors to promote seamless handovers and attain the IOC objectives (Cabitza et al., 2011). Ensuring the transmission of the correct data at the right moment contributes to the integration of the appropriate care services (Protti, 2009), allowing for overview achievement (Bossen & Jensen, 2014), which alleviates the decision-making process (Steele Gray et al., 2021). Indeed, creating an overview is one way to support care actors' awareness and provide them with the precise data needed to make decisions confidently. Therefore, some studies suggested using integrated documentation protocols that unify the

recorded data to enhance cooperation and reduce the isolation of the care actors (Atwal & Caldwell, 2002). At the same time, communication between the different parties engaged in the patient's treatment presents a central component that bolsters care coordination and permits efficient teamwork (Körner et al., 2016; Winthereik & Bansler, 2007). However, the distribution of those parties through the different organizations and settings hampers communication, as it must cross the organizational boundaries (Kadu & Stolee, 2015).

In summary, there is a constant and increased need for coordinated care services to enhance healthcare systems. IC is then needed to bring together the different stakeholders to ensure coherence and continuity of care. However, achieving IC is complex due to the complexity of healthcare systems. Previous work has demonstrated that sharing data and communicating are essential to permit overviewing, support cooperation among care actors, and help implement IC. Other works have discussed the role of IT in supporting sharing to support achieving an overview and promoting communication (Bains et al., 2018). Thus, to understand how IT can support achieving an overview to overcome the challenges faced by IC, we first need to understand how clinical overview is achieved in healthcare.

2.3 Clinical Overview and Medical Data to Support IC

Collecting, aligning, and analyzing medical data is the core activity enhancing medical decision-making. This activity is known as achieving a clinical overview (Bardram & Houben, 2018). Achieving clinical overview is defined by (Bossen & Jensen, 2014) as:

> *"How health care professionals arrive at a sufficiently informed, accountable, and coherent understanding of a situation, so that they are capable of acting consciously and with confidence"* (Bossen & Jensen, 2014, p. 1).

Indeed, acquiring an all-encompassing perspective is imperative for effective decision-making. Nevertheless, the extent of comprehensiveness and quantum of data required to attain such an overview is contingent upon the contextual circumstances, the obstacles encountered, and the temporal constraints faced by care actors (Bossen & Jensen, 2014; Levy-Fix, 2020). Consequently, care actors are constrained to prioritize the resource to consult to build the needed overview to solve emerging problems. Henceforth, they utilize a diverse range of artifacts, encompassing both physical and digital mediums, in conjunction with engaging in dialogues with patients, their relatives, and other relevant stakeholders during the various meetings and conferences (Bossen & Jensen, 2014). When individuals seek a concise and expedited representation of data, they often use charts and whiteboards to accentuate salient data points (Hertzum, 2017).

The type of data reviewed to achieve an overview can be organized into two categories (Lovis et al., 2000):

> 1) The structured data presenting the data stored within inputs, generally used to document the numerical data in the patient's charts (such as the vital signs).
>
> 2) The unstructured data presenting the descriptive text-based documents that can be further categorized within three categories (H. J. Tange et al., 1997): i) the core parts: encompassing the patient's medical histories, the providers' progress, and examination notes as well as the medication sheets; ii) the procedural reports: encompassing the different results of labs, radiology, etc.; and iii) the episode summaries encompassing the different discharge and referral letters.

Previous studies highlighted the critical role of unstructured medical data in healthcare activities (Lovis et al., 2000; Mønsted et al., 2011; Sultanum, Brudno, et al., 2018). Patient medical records contain a significant amount of unstructured data, which provide valuable insights into the patient's case (Mønsted et al., 2011; Sultanum, Brudno, et al., 2018). Moreover, unlike structured numerical data that are updated after each encounter or test, unstructured data tells stories about the patient's treatment evolution, including any emergent issues and those that have been treated. Thus, the produced documents cannot be updated or changed but serve as pointers depicting the patient's condition at a specific moment. Consequently, unstructured medical data allows for following the patients' cases as it represents the landmarks that highlight the various care episodes (Lovis et al., 2000). Moreover, alongside its use to manage the different healthcare processes such as billing, audit, medical research, and the different administrative activities (Almeida et al., 2012), it supports the cooperative aspect of the medical activities as it allows care actors to communicate and share the different data about the patient (Bringay, 2006; Winthereik & Vikkelsø, 2005). Henceforth, although structured data can provide a minimal overview, a thoroughly comprehensive overview necessitates the examination of unstructured data, which affords a more detailed perspective.

However, as we mentioned earlier, in the context of IC, the various produced medical data are fragmented through the various paper-based records and the Electronic Medical Records (EMRs) used locally by the various settings (Svensson, 2019). Within this context, providing standardized Electronic Health Records (EHRs - nationwide) is touted as an efficient way to overcome fragmentation and allow integrated access to medical data (Cresswell, Worth, et al., 2012). Therefore, to support overview achievement within the IC context, we must understand how to integrate the various EMRs.

2.4 Electronic Health Record Support for Overview in IC

EHRs play a considerable role in managing and succeeding patients' treatments by documenting, saving, accessing, and sharing data between the parties involved in the patient's care (Kim et al., 2021). At the same time, they are seen as a channel for data to cross borders to ensure the integration of the activities emerging between the different organizations. However, to fulfill the projected aims of implementing EHRs that support overview in the context of integrated care, two levels of integration are required: (1) the integration of the various siloed systems (for instance, the various EMRs) used by the different care actors and institutions; (2) the integration of the data stored within those systems. In the following sections, we describe the various mechanisms used to integrate data and to create unified systems aiming at offering an overview of patients' cases to ease and support care activities

2.4.1 Medical Data Integration

Medical data integration plays a pivotal role in the success of the integrated care program as it allows the gathering of the patient's dispersed medical data in one place to avoid data loss (Protti, 2009).

> "*Information integration is a complex process of combining multiple types of data from different sources into a single infrastructure, allowing multiple levels of users to access, edit, and contribute to an electronic record of health services (EHRs)"* (Leventer-Roberts & Balicer, 2017).

Therefore, when achieved, the integration of the medical data allows the care actors participating in the IC to keep track of the different convenient, efficient, and critical medical data that support

the various short and long-term decision-making processes set around patient-centered care. At the same time, it allows them to ensure coherence between their activities and consequently helps foster cooperation and the overall success of the IC programs (Leventer-Roberts & Balicer, 2017; Protti, 2009).

(Johnson et al., 2008) stressed that different types of data integration can be employed depending on the systems' performances. For example, (Leventer-Roberts & Balicer, 2017) classified the six different types of data integration:

1. ***Horizontal integration***: this type of integration merges different portions of data stored within a similar source type. For instance, it permits collecting the different data produced by the actors working in various departments within the same clinic. Within this type of integration, all the data sources and the collected data have the same weight and priority. The problem here resides in the consistency of the collected data, as the practices used to document it within the different records may defer from one provider to another. For example, one may use kilograms (kg) to track the patient's weight, while others may use pounds (lbs).
2. ***Vertical integration***: this type of integration combines different medical data generated by different types of sources in one database. For instance, the data collected during home care by different providers, who treat the patient using their medical records, are integrated into one unique record that guides the care delivered at home. Within this type of integration, the data needs to be presented hierarchically to identify the data sources and to facilitate the correlation of the various assessment and care plans. However, it faces prioritizing and ranking challenges. Those challenges emerge, especially during the interpretation steps when different care actors record various medical data simultaneously, which hampers identifying the most relevant problem. For instance, this is the case when the General Practitioner (GP) refers the patient to multiple specialists. In that case, specialists document their interventions separately. Then, when the GPs update their overview, they need help deciding which data to prioritize.
3. ***Historical integration:*** this type of integration combines the patient's medical data from various systems. The data is collected in various formats, including paper-based medical records. The gathered data needs to be processed and reviewed to facilitate the future use of this type of integration results.
4. ***Longitudinal integration***: this type of integration configures a dynamic gathering of medical data depending on the patient's emerging issues. Thus, the type and the moment of the data integration change according to the problems that appear and the ones that are treated. Therefore, the flexibility and the ability to add new types of medical data and entries are essential to process this integration.
5. ***Cross-indexing integration***: this type of integration merges the patient's medical data with their relatives to provide more details about the different issues faced by the different generations within the same family, which may relate. The synchronization between all the medical data to document all the related medical records presents a serious issue that requires a complex cross-indexing integration mechanism.
6. ***Alternative sources***: this type of integration takes advantage of the expansion of social media and self-monitoring devices to include the patient's medical data that is constantly generated. Merging this type of medical data provides a new angle of insight for the care actors to consider.

Yet, identifying the type of integration to opt for is challenging. Moreover, the complexity of data, which is context-related and embedded in the practices, is another difficulty (Protti, 2009). (Bjørnstad et al., 2017) discussed the issues arising when medical data from various systems are

sought to be integrated, interfering with the organization's practices. Integrating medical data from different EMRs is not merely a technical task; considering the organizational and social aspects is crucial to ensure the success of the integration. Therefore, based on (Carlile, 2004) framework depicting the possible ways to manage data when it crosses the boundaries of the organizations, (Bjørnstad et al., 2017) proposed three categories for data and system integration:

1. ***Systematic integration***: the data in this type of integration presents a common understanding for all the stakeholders working within the different organizations—for instance, the general patient data such as gender, age, and weight. Therefore, integration relies on the simple transfer of data.
2. ***Semantic integration***: the meaning and the connotation of the data type in this integration category are related to the organization and may be lost when it crosses its boundaries. Therefore, the data must be translated, based on established shared meanings, before its transfer to avoid misinterpretation. For instance, the name of a drug may be documented differently within different systems, which may hamper data integration.
3. ***Pragmatic integration***: this type of integration arises to manage the different conflicts that may appear when the stakeholders have different interests. Thus, more than translating the data is required to ensure the integration's success. Therefore, an agreement and negotiations are needed to handle all the accommodation. For instance, stakeholders may agree to rely on one unique system to "feed" the integrated system with conflicting data, like relying on the Electronic Medication Management System as the only source providing data about drugs.

In summary, merging medical data demands considering the type of data integration needed and paying attention to the various levels of the integration to ensure that the assembled data can still convey their meaning. Moreover, medical data is stored within heterogeneous sources in different formats. Therefore, supporting medical data integration must consider various approaches to ensure systems' interoperability.

2.4.2 Systems Interoperability to Support Medical Data Integration

As medical activities often span different healthcare settings, the multiple EMRs used in those different settings have to be integrated to ensure integrated and coherent care.

> *Integration refers to a moment in an interoperability timeline where different information systems are interconnected physically and logically to achieve solution delivery* (Sabooniha et al., 2012, p. 2)

However, integrating the diverse EMRs is arduous because each EMR functions as an isolated component to respond to the different settings' needs (W. Wang et al., 2005). Enabling communication between those components is also challenging because each system is programmed using a different language with a different architecture (*ibid*). Integrating EMRs then requires ensuring interoperability.

> *"Interoperability is the ability of an information system to use services and data from another information system. This exchange allows these systems to achieve a specified task in a given context and provides a continuous exchange of information between collaborating HIS."* (Sabooniha et al., 2012, p. 2)

(Protti, 2009) identified three approaches to ensure technical interoperability and integration to secure communication between the different EMRs:

1. ***The message-based integration***: To ensure this type of integration, the systems rely on communication protocols and the standardization of the shared data structure. This type of integration is more efficient when the communication systems and the data to exchange are identified ahead of the integration process. Through this configuration and using different standards, such as HL7 and DICOM, the different systems can exchange portions of the electronic medical records (Sabooniha et al., 2012).
2. ***The virtually federated integration***: is also known as pointing and indexing. Within this type of integration, the shared data are stored within the feeder systems. Each feeder system regularly sends an index of the location of each piece of data stored within its local storehouse. Receiving systems can read the data but cannot edit or update it. All feeder systems must maintain an online status for constant access to the distributed data. This configuration allows for easy updating of the list of feeder systems. The Distributed Electronic Health Record (DEHR) uses this type of integration. DEHR stores clinical documents in their original location, and cross-institutional patient identification allows for the consolidation of patient-centered documentation and access to different documents by relevant parties (Bergmann et al., 2005).
3. ***The physically federated integration***: is also referred to as publishing. In this integration configuration, feeder systems are linked to a mediator that provides data storage where all systems can write upon a prior agreement. Identifying the origin of the data presents a challenge, and updating the list of feeder systems requires mapping processes before new systems can publish new data. However, this configuration allows access to all medical data, even if the origin of the data is not online.

Alongside the technical interoperability, (Sabooniha et al., 2012) argued for the need to consider five other levels of interoperability, which include: 1) ***Syntactic interoperability*** depicting the different mechanisms allowing the systems to exchange the data. 2) ***Structural interoperability*** allows the creation of clinical models and domain concept agreements. 3) ***Semantic interoperability***, which intends to offer the capability to transport the data while preserving its meaning and ensuring that the receivers can understand it. 4) **O*perational interoperability*** represents a common understanding of administrative, clinical, and statistical data. 5) ***Organization interoperability*** requires the assimilation of the legislation, the roles, the processes, and the policies regulating the environment where the IC is emerging.

In summary, integrating medical data to create a centralized EHR that provides integrated access to a patient's data requires taking into account the type and level of integration needed and the approach to merging various data. Then, creating an overview requires careful attention to structuring, organizing, and visualizing integrated data.

2.4.3 Medical Data Navigation

Different ways to organize and navigate medical data in EHRs have been proposed to facilitate tracking, following, and analyzing medical data (Pieczkiewicz et al., 2007). In this section, we detail the different approaches to structuring medical data within the EHRs and creating visualization systems to ease the navigation within this content.

2.4.3.1 Organizing Medical Data within EHRs

While EHRs aim to provide the integrated data needed to assist medical work, no consensus on the adequate structure of medical records may facilitate their navigation. (H. Tange et al., 2017) have indeed identified three ways of structuring medical data in EHR:

1. ***Source-oriented***: This structure presents the oldest type of medical records' content organization (Reiser, 1991). The medical data within this type of EHRs is organized according to its origin and sources (Hayrinen et al., 2008). For instance, all the progress notes of a specialist are stored together within the same folder. Afterward, each source's content is sorted chronologically (H. Tange, 1996). This structure allows the care actors to navigate the domains within the patient's record. Moreover, the chronological order allows them to identify the new content inscribed within each domain (Buchanan, 2017).
2. ***Problem-oriented***: this type of structure was invented by Dr. Larry Weed in 1968 (Weed, 1968), who criticized the source/time organization and claimed that the patient's medical record needs to be organized according to the problems faced by the patient. Not only did he argue that this would be more suitable for medical work, but he also debated that this would allow the creation of records that would enhance the scientific, problem-solving aspect of medical work (ibid). The content (such as the progress notes) inside the Problem-Oriented Medical Records (POMR) is placed according to the problems discussed. The POMR was developed to create the SOAP note format containing the different Subjective, Objectives, Assessments, and Plans to structure the medical data within each problem (Salmon et al., 1996). Therefore, EHRs based on POMR display the problems list detailing the patient's current issues and the past ones that may still be relevant to the current situation (Simons et al., 2016). Care actors can navigate the SOAP notes to get further data about the patient's complaints, the diagnosis, the care plan, and the treatments (ibid). This structure helps the care actors quickly review the history of a patient's case (Salmon et al., 1996). Therefore, it eases linking medical problems, decision-making, and managing the population's health (Simons et al., 2016).
3. ***Goal-oriented:*** this type of structure involves patients and centralizes the medical record documentation around their goals to ease the decision-making process according to the patient's priorities (Mold et al., 2003). For instance, if patients want to maintain their autonomy for extended periods, their care plan must align with this goal (H. Tange et al., 2017). The shift to the goal-oriented medical record was motivated by the need to engage the patient as they represent an undeniable source of medical data (Nagykaldi et al., 2018). To implement this type of medical record, EHRs must integrate the patient's profile and a health planner to link the patient's goals and the other parts of the health record. Thus, every decision and note produced in the medical record needs to be linked to a patient's care preferences and goals. Therefore, this model allows the different users to maintain an overview of the patient's desires and work collaboratively to attain them (*ibid*).

2.4.3.2 Visualizing Medical Data

Different visualization techniques are suitable to present all the medical data in one place to support decision-making, administration, and research (Caban & Gotz, 2015). Indeed, the visual display of medical data is an efficient way to enhance the understanding of complex patient cases (Chittaro, 2001). However, visualizing the medical data is arduous (Kusunoki & Sarcevic, 2015). The temporal aspect of medical data that often shifts in priorities, and the constant rise of critical events, render their visualization challenging (ibid). Moreover, the large quantity and the heterogeneity of data to visualize (Aigner & Miksch, 2006) and the need to consider how to present the data flow according to each care actor (Caban & Gotz, 2015) add to the complexity of designing accurate visualization systems.

Therefore, to organize and offer data presentation in computer-based systems, Shneiderman (Shneiderman, 2003) proposed the mantra “overview first, zoom and filter, then details on demand." Indeed, allowing the users to move from a general overview to an elaborated one is

crucial as it allows them to get an insight first and then proceed to see details when needed (Bossen & Jensen, 2014; Kosara & Miksch, 2002). Moreover, (Yi et al., 2007) proposed the user intent model, which detailed a list of principles aiming to support the creation of interactive visualization by giving the possibility to readjust the data display and the chance to connect and refine the presentation. Alongside the possibility to personalize the visualization according to the user model, connecting and merging the different types of data allows the visualization of dependencies (Kosara & Miksch, 2002). Furthermore, studies argued for the need to build intuitive visualization that various users can review and read even if unfamiliar with the visualization's techniques (Kosara & Miksch, 2002; Rind et al., 2013).

There has been a significant focus on temporal visualizations that allow tracking of medical data's temporal evolution. Displaying medical data in temporal visualization is one way to enable the care actors to walk through the patient's case (Caban & Gotz, 2015; Craft et al., 2015; Thaduangta et al., 2016). These visualizations often involve observing numerical data flow or events inscribed in medical records (Aigner et al., 2007; Rind et al., 2013).

Various studies have suggested using numerical scales, graphs, color-coded and height-coded timelines to track the evolution of numerical data (Bade et al., 2004). These different techniques allow the users to track and follow the data stream and spot the drifts and anomalies that may occur (Aigner et al., 2007). The graphical summary of patient status (Powsner & Tufte, 1994) is one of the most known presentations of structured numerical data through time. In this representation, the numerical data is displayed through temporally sorted dots placed in the graph according to the laboratory reference value of the medicine's advised doses. Thus, the viewers can detect abnormal values. Other systems, such as Midgaard (Bade et al., 2004), offered different levels of visualization for the structured data (see Figure 2). Therefore, the first overview of the system is a prolonged colored background that represents a qualitative description of the values of a specific parameter. Each color represents the position of the parameter according to the referenced values. For instance, if the blood sugar level was low for 5 hours and then jumped to normal for another 2 hours, the system will display a red background for 5 hours, attached with a green background lasting for 2 hours. This visualization allows four other levels of details through a zoom-in of each level. The second level inscribes a label giving details on the value in each color (such as intervals of the actual value to visualize). On the third level, the interval of each color is transformed into bars. Then, the bars become a graph with a color-coded background to show the change in the values within this interval of time. The last level of detail presents a general graph where a horizontal line presents the transition point from one interval to another.

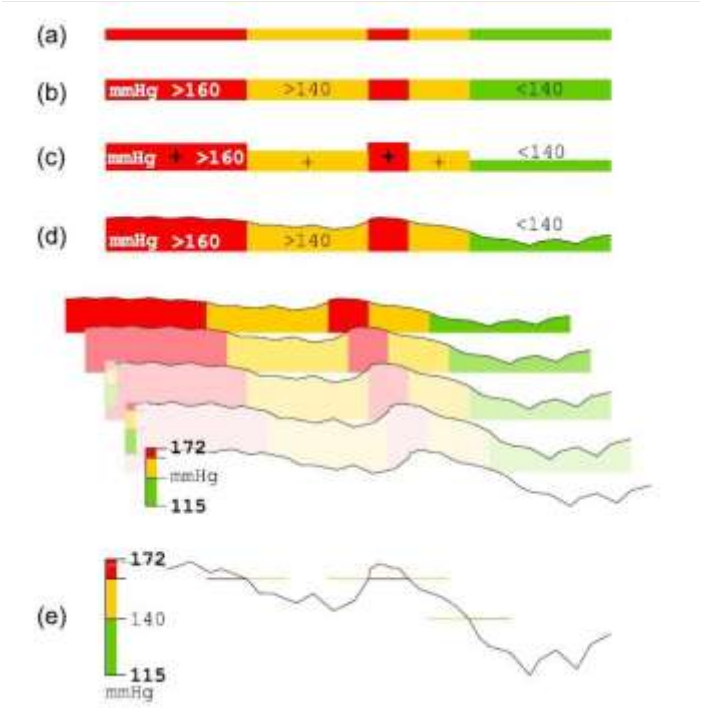


Figure 2 Midgaard (Bade et al., 2004) system

When it comes to visualizing and navigating the events inscribed within the medical record, many studies worked on extracting the medical data from the medical documents to display their content in the temporal-based presentation. One of the first systems to present medical records in lines was Lifelines (Plaisant et al., 1996), which relied on manually extracting medical data from medical documents. After extracting data from medical documents, Lifelines (Plaisant et al., 1996) presents medical events as vertical bars organized in facets representing the affected category (e.g., all events related to problems or diagnoses grouped within different facets). Each bar's length represents the event's duration, allowing care providers to track the evolution of care episodes and link them by understanding the succession of events.

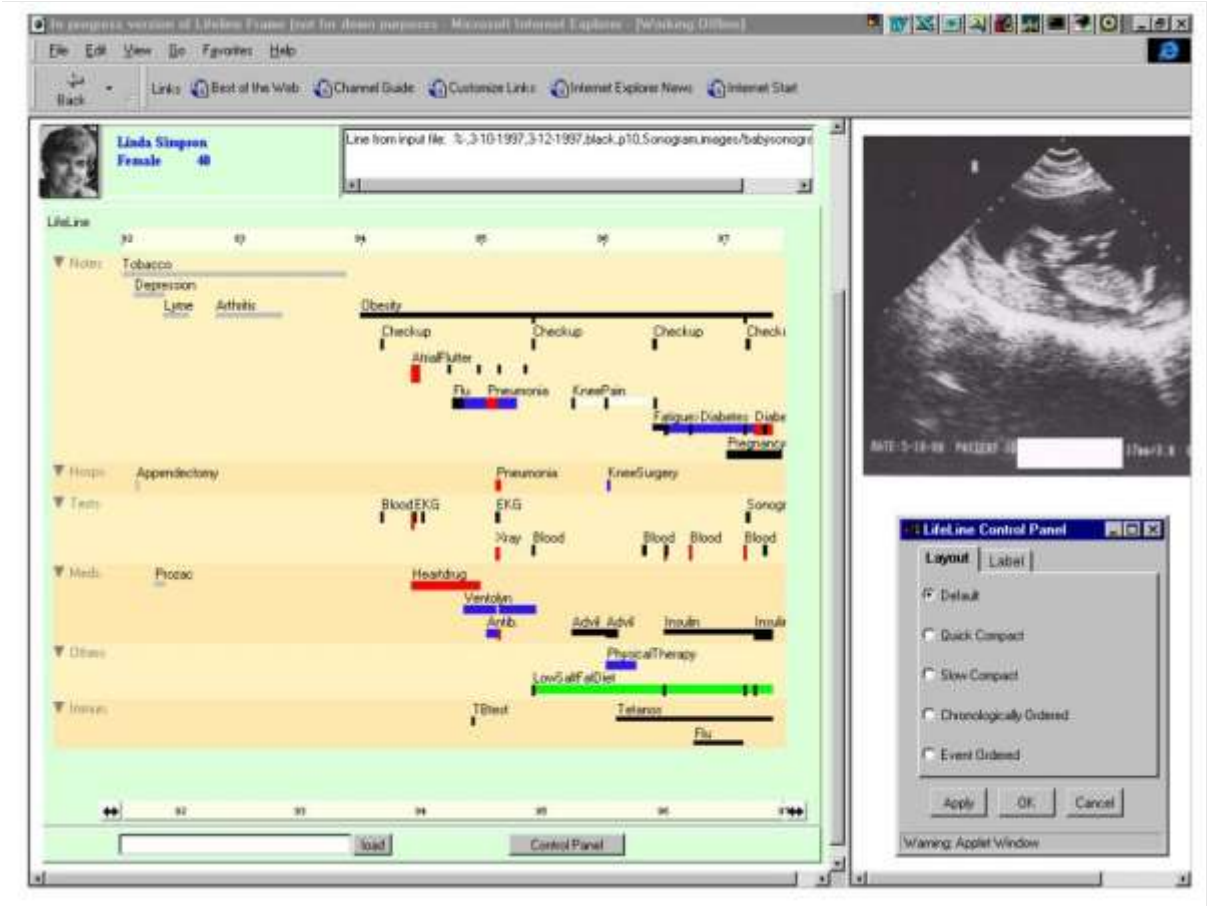


Figure 3 LifeLines the visualization of personal medical histories (Plaisant et al., 2003)

Other systems, like the integrated viewer (An et al., 2008) (see Figure 4), propose to visualize various heterogeneous medical data in integrated visualization. The system allows care providers to follow the development of different medical data types within the same interface. Based on the HL7 Reference Information Model (RIM), the tool aims to provide a unified platform for sharing and using data from different medical domains. To create the visualization, the tool classifies medical data into three categories: numeric data (e.g., vital signs), textual data (e.g., progress notes), and binary waveforms and images (e.g., ECG). The tool then combines techniques such as LifeLines and graphs to visualize the classified data.

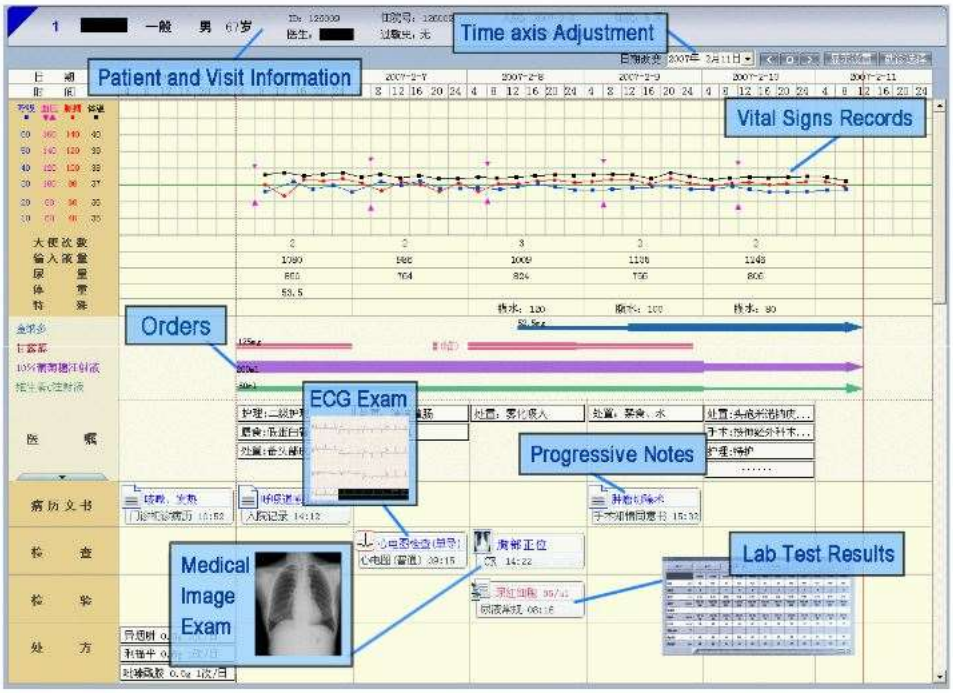


Figure 4 Integrated Viewer permits to visualize different types of medical data (An et al., 2008)

Moreover, to offer quick navigation through the text-based documents stored within the EHRs, many projects relied on the NLP techniques to explore the medical records content to create interactive systems (Kenei et al., 2020; Sultanum, Singh, et al., 2018; Thiessard et al., 2012; W. Wang et al., 2005). Those different projects extracted the content inscribed within each document to create semantic groups and organize the documents within those groups (ibid). Then, different features were provided, such as "the collections filter" that allows arranging the documents within hierarchies related to their semantic value (Sultanum, Singh, et al., 2018) or summaries, where the content of the documents is grouped within SOAP formats to facilitate the identification of the main issues and treatments (Kenei et al., 2020) (see Figure 5). Moreover, the NLP was used to afford features to compare and correlate the cohort of the medical documents (for instance, checking the documents referring to a particular medicine see Figure 6) (Q. Wang et al., 2021).

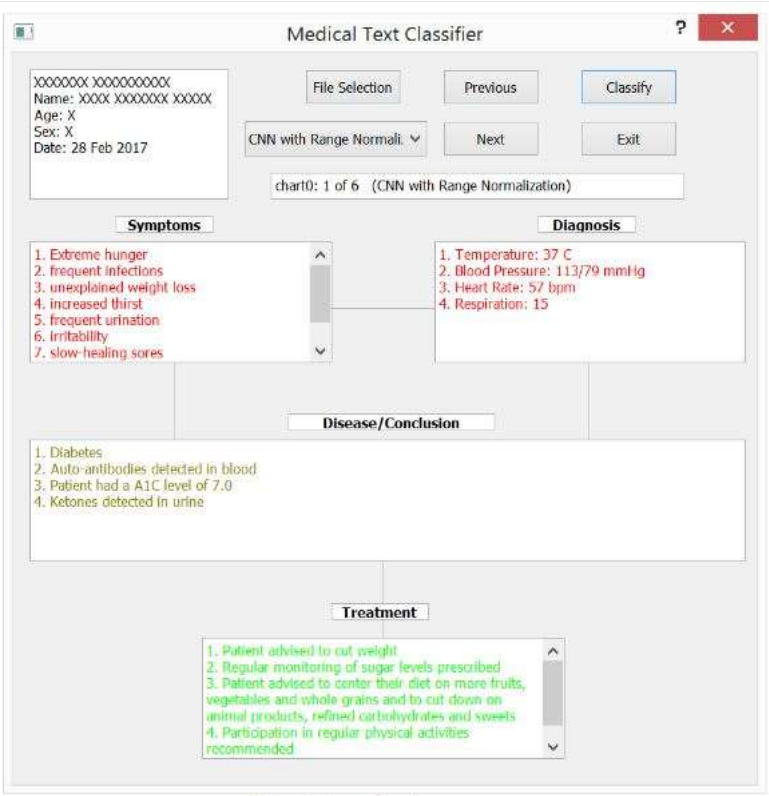


Figure 5 Medical text classifier presenting the medical data inscribed within documents using SOAP format (Kenei et al., 2020)

2.4.4 Limits of Current EHRs in Supporting IC

While the efforts to promote the integration of EMRs to ensure the success of IC are proliferating (Fitzpatrick & Ellingsen, 2013), different studies debated the lack of their impact in supporting clinical practices (S. A. Martin & Sinsky, 2016; Mateo-Abad et al., 2020; Piera-Jiménez et al., 2020). Different reasons can explain the failure of the different developed systems to fulfill the care actors' needs.

Previous work in CSCW assessed that the deployed systems often overlook the intricacies of the actual work practices, such as documentation and ordering, and instead focus on redesigning the overall workflow (Jagannath et al., 2019; Overton, 2019). Indeed, one of the salient debated issues is the focus on the documentation practices that support the administration, billing, and audit activities on behalf of the clinical activities (Adamson et al., 2020; S. A. Martin & Sinsky, 2016). Consequently, care actors generally delay documenting their intervention (Priestman et al., 2018), leading to incomplete and outdated systems (Shah & Khan, 2020). (Adamson et al., 2020) argued that creating documentation spaces where care actors can record their interventions without administrative restriction would foster integration and cooperation between the different actors.

Furthermore, scholars have asserted that designers and implementers of medical information systems often fail to adequately assess the existing reality, resulting in a discrepancy between the intended design and the actual implementation. This misalignment between reality and design is primarily perpetuated by insufficient data provided to end-users and work procedures that do not align with the established workflows (Greenhalgh et al., 2010; Heeks, 2006).

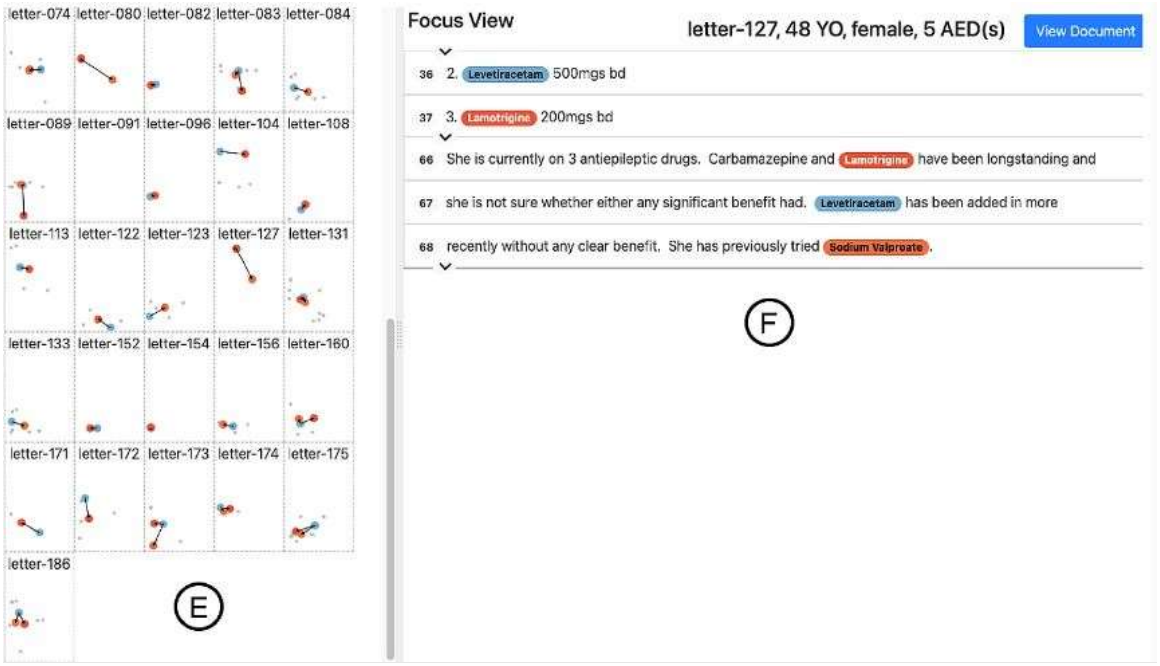


Figure 6 LetterViz viewer that allows users to position terms in medical letters with different levels of details (Q. Wang et al., 2021)

At the same time, as we have seen above, integrating data and systems requires considering the semantic aspect to avoid any misinterpretation and meaning loss (Bjørnstad et al., 2017). Thus, different approaches were proposed to provide semantic interoperability (Pedersen et al., 2017). However, different studies (Abou amsha et al., 2020; Richter et al., 2016) argued the importance of direct communication between the different care actors to contextualize the data and foster the collective sense-making and the construction of a collective overview of a patient's case. Thus, supplementing integrated systems such as the EHRs with communication systems support communication among care actors (Richter et al., 2016).

Moreover, the integration of the different siloed systems encompassing large quantities of data creates integrated systems that offer data that is hard to read (Borland et al., 2014; Caban & Gotz, 2015; Wongsuphasawat et al., 2011) and that is not efficient for the different care actors from various backgrounds (Kneck et al., 2019). Indeed, the encounters in the context of IC are becoming curtailed and centered around problems (Hilty et al., 2018). Thus, care actors struggle to coalesce the necessary data to make decisions (Steele Gray et al., 2021). Therefore, research focused on structuring and creating computer-based visualization systems that support the navigation of the EHRs to achieve an overview of the patient's case and to spot the emerging problems and events that occur in this case (Buchanan, 2017; Rind et al., 2013; Weed, 1968).

However, independently of the structure, browsing medical data is based on hierarchies, as the different content is located within folders that pinpoint their sources, problems, and goals. However, several studies claimed that navigating a hierarchical folder is less compelling, especially when the user looks for a certain piece of data and spends their time scrolling through the different folders to find the data needed (Mosweunyane et al., 2011). Moreover, creating those hierarchies causes record fragmentation, hindering the construction of the patient's overview (Buchanan, 2017). At the same time, merging different types of medical data within the same folders assumes that the value of the different content is similar for the different care actors (Amir et al., 2015; Corry et al., 2006; Feufel et al., 2011). However, the information's needs depend on the care actors using the system; for instance, it is common practice to collate a referral letter that invites a specialist to participate in the care, and a medical prescription, which provides a plan

for the administration of medication, both of which are issued by a hospital in a singular folder. Nevertheless, it is discernible that these documents do not hold equivalent significance to the specialist responsible for the patient's care and the nurse in charge of executing the medication regimen. Therefore, to overcome these challenges, different studies argued for the need to create computer-based visualization systems that support medical records navigation and enhance the creation of overviews (Rind et al., 2013).

Moreover, the broad work on medical data visualization focused on the visualization of structured data or extracted and exhibited the content of unstructured data. However, different studies discussed the role of the medical document as a whole element forming landmarks permitting the navigation of the different episodes of the patient trajectory (Lovis et al., 2000; Mønsted, 2015). This is especially true in IC, where they form an essential piece of data (Almeida et al., 2012). Moreover, the relevance and the benefit of using different data vary according to the various care actors' needs (Amir et al., 2015). Therefore, focusing on the visualization of the extracted data rather than the whole element may hinder achieving an overview of the patient's case and hamper the cooperative work. Furthermore, the visualization techniques used to present the medical data tend to use graphs, charts, and metrics (Rind et al., 2013). While a numerical presentation might be helpful in situations like intensive care units or emergency departments (Iftikhar et al., 2019), it may not be sufficient for managing the overall progress of care. Care actors need more contextual data to make informed decisions, especially when critical information is missing. They rely on context information to bridge the gap and make the best decisions based on the evolving situation.

In summary, supporting achieving an overview of patients' cases is a complex undertaking that transcends a mere technical exercise. It requires understanding the practices of overviewing the patient's case before exploring the type of data integration approach, how to merge this data from the various siloed system, or how to display the aggregated data to respond to the needs of the different care actors. Moreover, considering those practices sheds light on the crucial role of unstructured data. Therefore, systems supporting overviewing should consider how to present this type of medical data to respond to the emerging needs of care actors.

2.5 Documents Navigation

Documents are essential in a fluid information stream within different organizations (Coffey, 2014). Their wide use resulted in extensive collections of documents to support work activities (Almeida et al., 2012). These documents' collections encompass different heterogeneous types of content (text, images) used to depict facts or narrate stories, which makes the activity of overviewing the collection a cumbersome task (Strobelt et al., 2009). Therefore, different studies tackled how they can be reviewed, visualized, and assimilated (Gan et al., 2014; Heimerl et al., 2016).

Within operating systems, the traditional file management systems (like Microsoft Windows Explorer and Apple Finder) displayed documents and files within folders that offered hierarchical navigation. Moreover, during the last decade, the Electronic Document Management System (EDMS) emerged as a new technological solution to manage the growing use of electronic documents and the digitization of paper-based ones. Those tools are touted as the best way to provide organizations with a common place to store documents with an easy retrieval process (Agarwal & C. Poo, 2006). However, the problem of navigation through the growing number of generated documents persisted. Therefore, much research focused on defining guidelines for designing EDMS to facilitate navigating different documents. Taxonomies, facets, and ontologies are practical ways to organize documents within EDMs (ibid). However, (Mosweunyane et al.,

2011) criticized those hierarchical representations and argued for the need to flatten those hierarchies to offer more appropriate navigation through the folders by using the document's metadata. To enhance the list-based visualization, other studies argued that providing a summary of each document could enable the user to gain an overview of the tenor of the different documents and therefore guide their navigation (Agarwal & C. Poo, 2006). Systems such as Document Cards (Strobelt et al., 2009) adopted this solution and represented each document by a summarization using the demonstrative key terms existing in each document and a filtered set of the figures in each file. Within Document Cards (see Figure 7), each document is represented by a card on an information landscape permitting zooming and moving interaction. At the same time, to ensure a general overview, documents can be grouped depending on different options, e.g., their belonging collection or alphabetic grouping. Moreover, the tool provides collaborative interaction by enabling the users to rate the documents to determine their favorite ones and suggest them as a reading option for their collaborators. At the same time, they can directly exchange those chosen documents to suggest them as coming reading (ibid).

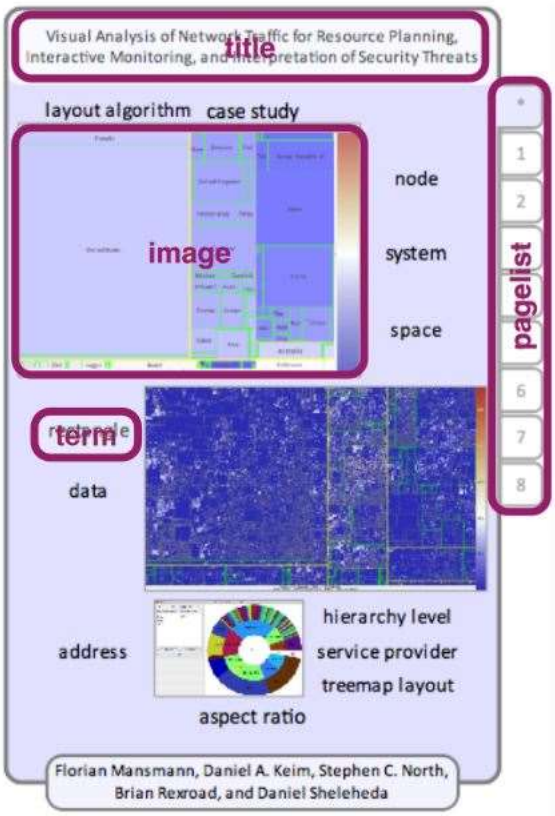


Figure 7 Illustration of the main region used to present the content of a document within a DocumentCard (Strobelt et al., 2009)

Moreover, to encounter the disadvantage of the list-based representation, other systems displayed the documents in a two-dimensional canvas (Wong et al., 2011), such as INVISQUE (see Figure 8), which previewed documents in two user-defined semantics dimensional spatial canvas. Thus, documents are ordered in the x-axis and y-axis, e.g., when visualizing research papers, the x-axis represents the publication date, and the y-axis displays the number of citations. Within this representation, each document is presented through a card containing basic information about the documents, such as their titles, descriptive keywords, and a brief resume. Then, the users can search and create different clusters to organize their documents directly from the canvas. Moreover, other studies favored matching documents with similar semantic content (Collins et

al., 2009; Rusu et al., 2009). Therefore, matched documents are clustered depending on their similarities and differences to provide the users with a clear vision of the essential themes and patterns presented in the extensive collection of documents. WordleNet (X. Wang et al., 2020) presents one of those systems that group scientific papers according to the similarities in their content inside word clouds. At the same time, the system allowed spotting the differences between the various groups presented by the distance between each cloud. Moreover, it allowed linking the different documents to provide information about the reference between them.

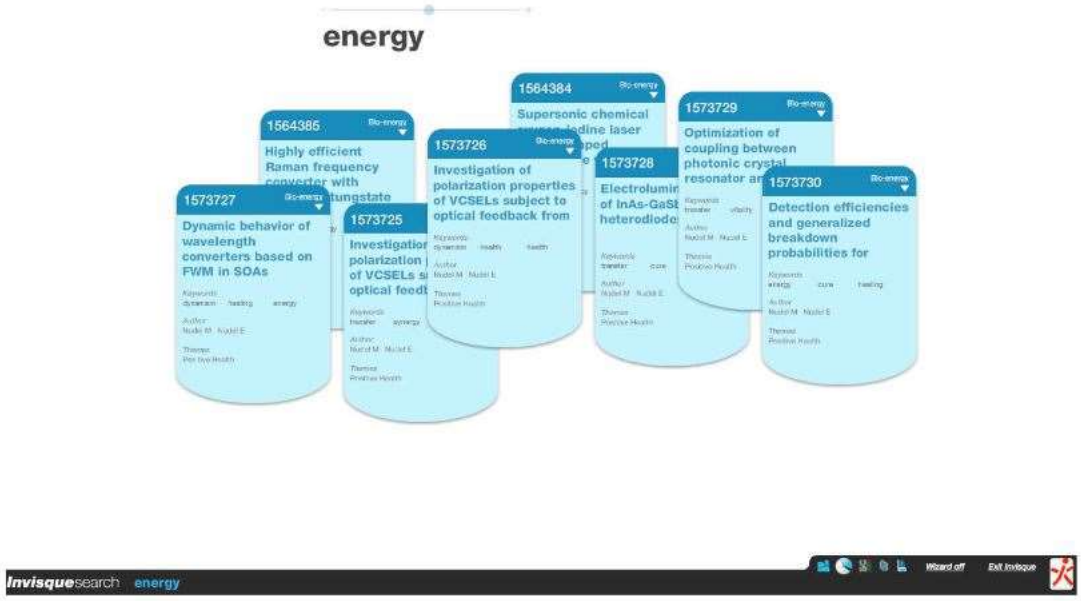


Figure 8 INVISQUE viewer displaying the result of query in 2D canvas (Wong et al., 2011)

Finally, other works (Elshaweesh et al., 2017; Gauch et al., 2007) intended to provide personalized navigation based on the user's preferences and interactions. Therefore, projects such as the user interest model (Li & Zhong, 2012) were proposed to build user profiles that describe their personal information, preferences, and previous interaction with the data. Then, the navigation systems display the most accurate content that matches the user's profile (Gauch et al., 2007; Hawalah & Fasli, 2015).

2.6 Conclusion

Existing literature provides insights into the role of achieving an overview to support awareness and the challenges hindering supporting this overview in inter-organizational cooperation. Therefore, the reviewed work stressed the need to consider cooperative practices to design technologies that support overview achievement.

Integrated care is an interesting field to observe the need for inter-organizational cooperation. Therefore, it illustrated the various challenges hindering joint actions and the struggle of the care actors to create an overview of the patient's case, permitting them to ensure the coherence of their activities. Integrating the various EMRs into standardized and centralized EHRs was offered as a solution to encounter the fragmentation of actors within IC, allowing data sharing to build patients' cases overview. However, our literature review also showed that: 1) integration is not only a technical issue; practices must be considered to design systems and to preserve the context of the integrated data; 2) providing complete EHRs is not suitable as it encumbers the care actors with huge quantities of medical data to review. Thus, we reviewed the existing approaches to

structure the medical data within the various EHRs and the previous work on creating visualization systems that ease the navigation of medical data to facilitate overviewing. We identified the shortcomings of presenting medical data in hierarchical structures and focusing on visualizing the structured numerical data.

Therefore, in our research work, we adopt a practice-centered computing approach: we investigate the care actors' practices of assembling the medical data to construct the overview needed to support their cooperation within an IC context. Then, based on this understanding, we explore how to support those practices through technology.

By investigating overviewing within inter-organizational cooperation, we contribute to the CSCW studies by extending the discussion about the role overview to support awareness to overcome the challenges hindering inter-organizational cooperation. Furthermore, by focusing on the design of visualization tools that support overview, we contribute to the health informatics community by proposing to adopt the practice-based approach to design the cooperative information systems supporting those new organizations in healthcare.

Our work contributes to the literature investigating cooperative practices within integrated care contexts. Compared to previous work, our research focuses on different care actors with different types of activities ranging between private practices and employed professionals with no shared system to facilitate their cooperative work to join the new integrated care pathways.

Chapter 3: Case Study

This chapter explores how care actors in Aube County (N-E France) work cooperatively across various care settings to establish an overview of the patient's case, ensuring coherence and continuity of care. The chapter is divided into four sections. The first section introduces the French context and the organizational and technological attempts to achieve integrated care. The second section outlines the methodology used to investigate the cooperative practices of care actors and how they create and use patient overviews. The third section presents the results of the analysis of empirical data collected. Finally, the chapter concludes with a discussion of the results.

3.1 Context

This section provides insight into the French healthcare system and its challenges, which have led to considering integrated care as a solution. First, we describe the system's state before 2018, when policies and technological solutions were evolving separately. We then introduce the "MaSanté 2022" health reform plan, launched in 2018 to encourage cooperation between medical, medico-social, and social actors, and which specifically identified technological solutions to support the defined policies. After this historical overview, we focused on implementing this plan in Aube County, where we conducted fieldwork.

3.1.1 An Overview of the French Healthcare System Before 2018

During the last decade, the performance of the French healthcare system has been subject to constant criticism (Bajeux et al., 2021) related to the failure of the system to provide equal access to healthcare services (Moyal & Fournier, 2022) for all residents, regardless of where they live or their income. Indeed, the French Ministry of Solidarity and Health pointed out, in a report published in 2018, the struggle of patients living in some territories to book urgent medical appointments, find a general practitioner, or guidance to the institutions that may provide answers to their needs (Bertrand et al., 2019). Finding available care actors has become more and more difficult due to the aging of the medical population and the unbalanced geographical distribution of the various care actors and care institutions, which led to qualifying certain areas of "déserts médicaux" (medical deserts) (Dumontet & Chevillard, 2020). Consequently, with the increase of the prompt medical demand, hospitals' emergency departments become overcrowded and cannot face the demand anymore (Granger, 2019).

Moreover, with the population over 60 representing now over a quarter of the French population (around 2 million persons) (Bajeux et al., 2021), the current system fails to deliver the complex care services needed to treat this population which often suffers from multiple chronic diseases that interlace (Perone et al., 2015). The system stumbles to support the coordination of all the needed actions, mainly because of the fragmentation and compartmentalization of the healthcare system (El Saïr et al., 2022).

This fragmentation is present at different levels; first, at the national level, policies on care and services are defined by two different departments within the Ministry of Health and Solidarity, which governs the provision of medical and social care and the creation of laws and policies (Bajeux et al., 2021). Within this configuration, the healthcare and social services are managed in one department (Directorate General of Healthcare Provision), and the public policies for solidarity and the promotion of equality in another (Directorate General of Social Cohesion).

Secondly, at the regional level, medical and paramedical care actors are fragmented (Moyal & Fournier, 2022), and their statuses differ (Lussier, 2020), which splinters the provision of care by the city (by the self-governing actors within the private practice), and the hospital (Granger, 2019). Consequently, the current structure caused the reluctance of the different stakeholders to engage in systematic cooperation due to the various cultures, interests, and the fear of losing their Autonomy (Lussier, 2020).

Facing this situation, the French government has launched several reforms to reorganize the healthcare system during the last two decades, aiming at a more efficient structure and management and promoting stakeholder cooperation (Bajeux et al., 2021; Granger, 2019). Figure 9 illustrates the evolution of organizational and technological solutions before 2018.

3.1.1.1 Organizational Solutions

The French government proposed reforms focusing first on hospitals through the hospitalization law in 1991, the creation of regional hospitalization agencies, and the health cooperation groups in 1996 (Moyal & Fournier, 2022). Afterward, the reforms focused on reorganizing healthcare services outside the hospitals. First, the assigned physicians' law was passed in 2004. It invited patients to nominate an assigned physician (who can be an actor with a private practice or an employed one). The aim was to define a coordinator of the patients' cases and a medical records manager[2]. Then, multidisciplinary health centers MSP[3] were formed in 2007. These centers have at least three general practitioners and one paramedic (a nurse, a dietician, etc.). The aim was to encourage care actors with private practice to settle collectively in structures around coordinated health projects[4]. Next, to reorganize the care and governance at the regional level, in 2010 regional health agencies (ARS[5]) were created. They are responsible for managing the medical and social care and related financial aspects and providing guidance for caring for elderly people (Bajeux et al., 2021).

Then, in 2016, the territorial health professional community CPTS[6] were created. They bring together professionals from a territory who wish to organize themselves around a health project that responds to local issues[7]. The same year, the primary care teams ESP[8] were created to offer a new approach to coordinating care to enhance the patient's pathways[9]. These teams gather primary healthcare professionals such as GPs, nurses, physiotherapists, pharmacists, etc., so they coordinate their actions around medical issues.

In 2017, the government presented a plan to "strengthen territorial access to care [10]" to diminish the difficulty of finding a general practitioner or a paramedical actor. Thus, care actors were accompanied to settle in rural areas, also with financial aid. At the same time, the government suggested combining salaried and private practices and favored outpatient internships for students (Moyal & Fournier, 2022). Moreover, to cover the rural territories' needs and reduce the

[2]https://www.legifrance.gouv.fr/jorf/id/JORFTEXT000000625158/#:~:text=%C2%AB%20Le%20m%C3%A9d ecin%20traitant%20peut%20%C3%AAtre,action%20sociale%20et%20des%20familles.
[3] Maison de santé pluridisciplinaire
[4] https://solidarites-sante.gouv.fr/systeme-de-sante-et-medico-social/structures-de-soins/article/les-maisons-de-sante-300889
[5] Agence régionale de santé
[6] Communauté professionnelle territoriale de santé
[7] https://www.ars.sante.fr/les-communautes-professionnelles-territoriales-de-sante
[8] Equipe de soin primaire
[9] https://www.fmfpro.org/monter-une-equipe-de-soins-primaires-esp-comment-et-pourquoi/
[10] Renforcer l'accès territorial aux soins

burden of the hospitals, medical students were obliged to hold their internships in the ambulatory sector and were offered the title of "assistant physician" when working in rural areas (*ibid*).

Overall, the different reforms aimed to foster the integration of the healthcare system by giving the patient a unique entry point, facilitating the management of cases by multidisciplinary teams, and detailing the admissions criteria (Bajeux et al., 2021). The MAIA[11] (Method of Action for Integration of Health and Social care in the field of Autonomy), created in 2014, presents one of the first experimental schemes to integrate the different medical, psychological, social, and administrative actors to ensure care delivery and the optimization of pathways for the patients over 75 years facing a risk to lose their Autonomy (Bajeux et al., 2021; Rizoulières, 2021). MAIA promotes stakeholder cooperation to improve the care pathways' management and prevent unnecessary hospitalizations. Therefore, the MAIA offered information and guidance about the available medical and social resources and insisted on creating case managers to support the organization of complex trajectories. Later on, in 2018, the government created new organizational concepts such as "mobile geriatric teams" and "advanced practice nurses," introduced new roles for clinical pharmacists to ensure the integration of care by merging the healthcare services, and created legal frameworks for information sharing (Bajeux et al., 2021).

While the different reforms created new organizational concepts and roles and promoted cooperation between the different care actors, the link between the public and private sectors was not considered till 2018 in the new plan called "MaSanté 2022".

3.1.1.2 Technological Solutions

The public health law voted in 2004 focused on information sharing as a central element to ensure effectiveness and continuity of care (Bourret, 2010). Therefore, the French government invested in creating a centralized EHR called DMP (For Dossier Médical Personnel "Personnel Medical record" for its first launch in 2006, then changed to Dossier Médical Partagé "Shared Medical record" in 2008). This endeavor aimed to prevent patient information fragmentation and promote information exchange among care actors (ibid).

The DMP aims to afford a unique central place where the most essential produced documents about the patients (such as summaries, lab results, etc.), following the different encounters, are stored to allow following the patient's trajectory (Burnel, 2018). While the system targeted to support and enhance the coordination of care by allowing access to patients' data, its creation model was based on the opt-in model to respect the laws, giving the patient the authority to allow the creation of their DMP and to define and restrict the access permissions to the different care actors around him (Seroussi & Bouaud, 2017). Moreover, patients are the managers of the content of their DMP, meaning they have the full right to exclude, remove, or hide the content they do not want some care actors to see (Bourret, 2010). The content can then have different statuses: 1) Open: which can be accessed by the patient as well as the different care actors that they have authorized; 2) Hidden: which can only be spotted and accessed by the document's author, the patient, and the patient's assigned physician; and 3) Sensitive: which presents the documents encompassing sensitive information that needs to be temporarily hidden to the patient (Seroussi & Bouaud, 2017).

Although the ambition of the government to generalize the use of the DMP, the adoption of the system was a failure (In 2016, only 1.5 % of the targeted population created a DMP, of which 41% was empty (Seroussi & Bouaud, 2017)), this outcome persisted despite the system being (re)launched in 2010 and 2016. Then, different features (such as the automatic push of

[11] Méthode d'action pour l'intégration des services d'aide et de soins dans le champ de l'autonomie

documents in the DMP and the possibility of creating the record by the patient) were added to the system in 2018 with the hope that it would encourage its use. Following these updates, around seven million records were created, and the content percentage rose to 20.9% in 2019 (Séroussi & Bouaud, 2020). However, the DMP is still not embedded in the daily practices of the care actors. It is treated as an additional artifact on top of the different EMRs they use in their offices (*ibid*). The literature discussed many reasons that hinder the adoption and use of the DMP. For instance (Bourret, 2010) stressed that the DMP assumed that the different care actors would have the same information needs, while each of those care actors hoped to have similar data to the ones they chose to store in their EMR. Moreover, (Burnel, 2018) highlighted the gap between the system's goals and the actual practices resulting in the DMP causing an extra workload. Furthermore, this work underlined that the care actors were worried about the possible misinterpretation and the loss of context due to the deferred reading of the records by other care actors that may have more updates about the patient's case.

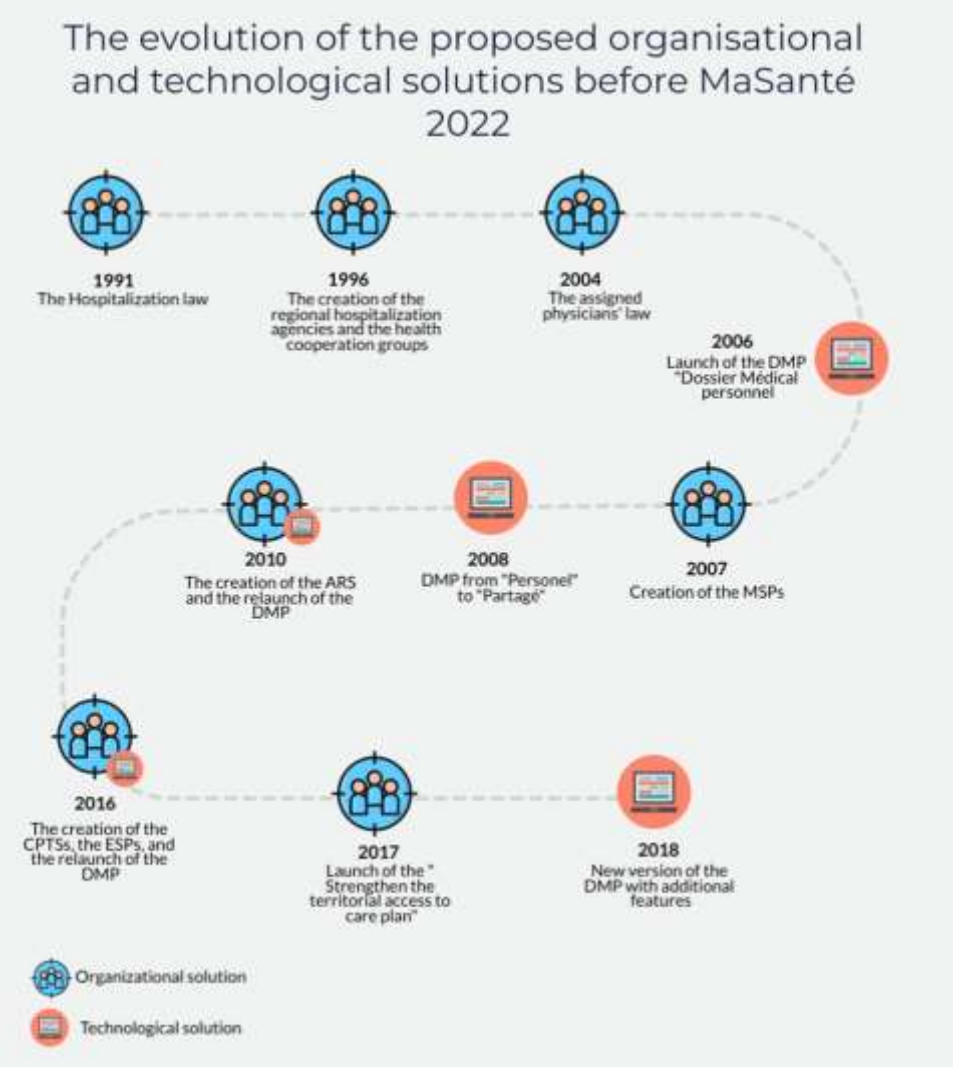


Figure 9 The evolution of the different organizational and technological solutions

3.1.2 MaSanté 2022

In 2018, the French government unveiled "MaSanté 2022, un engagement collectif" (My Health 2022, a collective commitment), a plan defining the policies and the strategy of the healthcare system for a five-year term. Therefore, the plan detailed 54 rules grouped into nine sectors: territorial structuring of care; adaptation of vocational training; gradation of care and evolution of regional hospital groups; evolution of managerial skills (especially medical) in the hospital; regulation and unscheduled care; diversification of working conditions and career paths; quality and relevance of care; digital health; financing and pricing (Ministère des Solidarités et de la Santé, 2018). In this section, we focus on the organizational structure of the healthcare system and the digital health strategy.

3.1.2.1 The Organizational Structure of the Healthcare System within MaSanté 2022

The main goal of MaSanté 2022 is to enhance proximity care and the first recourse (Bajeux et al., 2021). Different ways of organizing care in the city and the hospital were defined to fulfill this goal.

When it comes to the hospital, MaSanté categorized the existing hospitals into three levels to increase the number of beds reserved for primary care. The first level encompasses labeled structures called proximity hospitals, "hôpitaux de proximité" that carry out local hospital missions (general practice, elderly care, follow-up and rehabilitation care, specialty consultations, and unscheduled consultations). The proximity hospitals provide technical platforms (imaging, biology, and explorations) that care actors with private practice can use. When needed and upon coordination with the CPTS[12], patients can be referred to the second level offering more specialized establishments, such as a hospital center specialized in surgery and maternity, or a third-level structure offering hyper-specialized services, such as university hospital centers (Moyal & Fournier, 2022).

The government has promoted the creation of CPTSs (community professional territorial health care teams) to encourage integrated care practices within private practices. The goal is to reach 1000 CPTSs and encourage all care actors to join these teams to benefit from financial aid and reduce isolated activities (Granger, 2019). Those CPTSs, working under the supervision of the ARS are granted the responsibility for planning care provision (Bajeux et al., 2021). MaSanté 2022 also created territorial support platforms (PTA)[13] that merge different organizations (such as the MAIA, PAERPA[14], CLIC[15], etc.) and then integrated the provision of care for older people (Rizoulières, 2021). Those PTAs aim to offer a single information point for the care actors and the patients to coordinate the complex pathways (*ibid*). Furthermore, a new profile called medical assistant was created. Those medical assistants are in charge of simple medical actions (such as taking blood pressure and fever) to free up some time for the actors with private practice, therefore allowing them to treat more patients to prevent the saturation of the hospitals' emergency departments (Granger, 2019).

In this context, the French Hospital Federation FHF launched in 2018 a trial for a population-based approach, which is derived from the "Triple Aim" established in Québec in 2010 [16]. This trial aimed to bring together different stakeholders in five territories: Aube and Sézannais, la Cornouaille, Le Douaisis, Les Deux-Sèvres, and Haute-Saône to treat two populations, patients

[12] Les communautés professionnelles territoriales de santé
[13] Plateformes territoriales d'appui
[14] Personnes âgées en risque de perte d'autonomie
[15] Centre locaux d'information et de coordination
[16] https://www.fhf.fr/la-fhf-en-action-responsabilite-populationnelle-tous-acteurs-de-notre-sante

with and at risk of type 2 diabetes and those at risk of heart failure (Gomez et al., 2020). This approach has a "fourfold objective": an improvement of the quality of clinical services, ensuring better health of the population, better use of resources and greater efficiency of expenditure, and a revision of the working conditions of professionals, which are essential to ensure the sustainability of the healthcare system (El Saïr et al., 2022). The trial focused on the five territories to adjust the care services to correspond to the needs of each territory depending on the existing care offers (which may include prevention actions, rehabilitation, re-education, and end-of-life support) (Lussier, 2020). This population-based approach is led by a consortium formed by the Territorial hospital group GHTs[17] and the actors with private practices, particularly the CPTS. This consortium works to develop shared action programs for the chosen populations. These programs are based on a medico-economic and clinical stratification of the health needs of these populations and the systematic implementation of best practices (El Saïr et al., 2022).

Alongside those different organizational solutions to improve the French healthcare system, the government worked on a digital project called “Accelerating the digital shift” to favor the coordination of care (Rizoulières, 2021).

3.1.2.2 The French Digital Health Strategy

MaSanté 2022 assumes that the healthcare system of the near future has to count on new alliances between the medical and social actors, the care that private actors provide, and the one provided by hospital professionals. It is posited that such cooperation can only be effective with the support of advanced digital technologies that enable the high-performance delivery of healthcare services (Granger, 2019). Therefore, the government defined five directions to accelerate the digital shift (see Figure 10) (Ministère de la santé et de la prévention, 2019). In this section, we give details about the different actions taken in the four first directions:

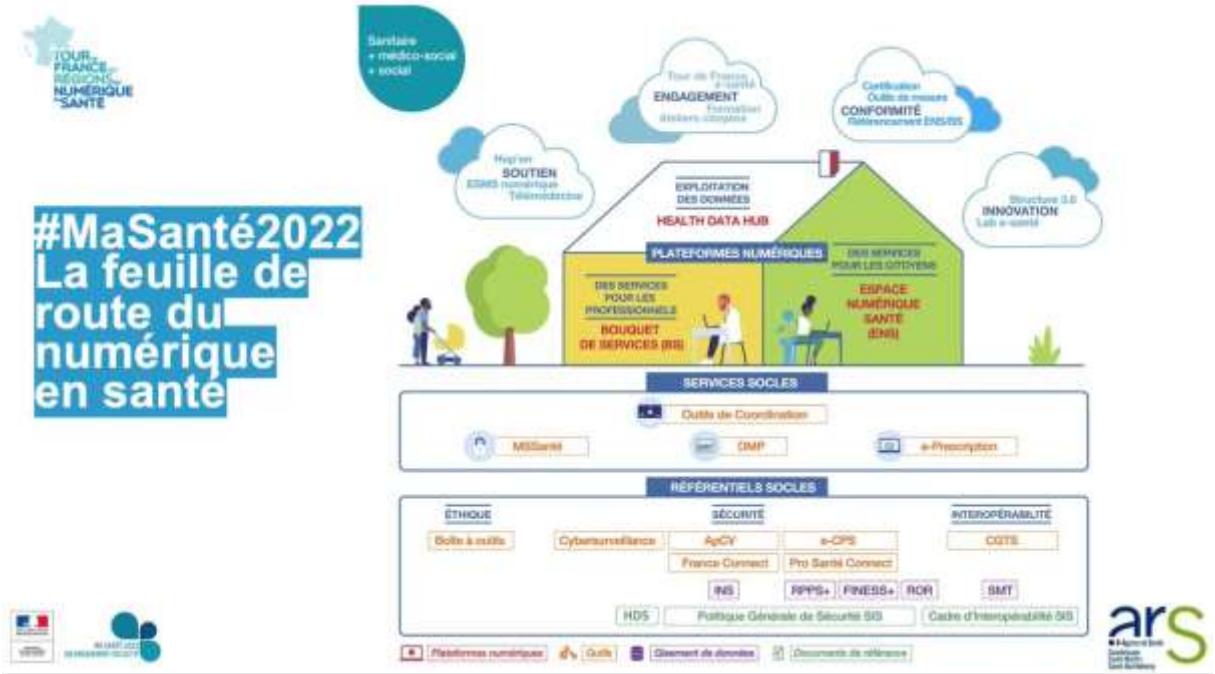


Figure 10 "Maison e-santé", the different levels of the digital tools (Ministère de la santé et de la prévention, 2019)

[17] Groupement hospitalier de territoire

1. **Strengthening digital health governance**: The ministerial delegation will manage all digital transformation projects for digital health DNS[18], attached to the Minister of Solidarity and Health. It will ensure tight control of the digital health agency ANS[19], which focuses on the operational implementation of the digital health policy.
2. **Intensify the security and interoperability of health information systems (Référentiels socles)**:
    a. Unify the digital identification of the care actors, i.e., all care actors using and editing the health information system. Thus, all the care actors must update their EMRs to be Ségur[20] compatible. Therefore, the used EMRs would encompass standardized features that prevent double entries in the DMP, dematerialize prescriptions, and offer standardized communication channels. Moreover, by following Ségur, the EMRs would use a unified authentication service called ProSanté connect[21] to ensure a secured connection and access to the tools such as DMP and the secure messaging service;
    b. Create and foster the use of the digitalized versions of the various means of authentication (such as the health insurance card, the Vitale card app, or the Healthcare Professional Cards e-CPS[22]) to secure access to teleservices.
    c. Propose the deployment of the national health identifier (INS[23]) to ensure that the same patient is uniquely recognized in all the EMRs. Therefore, while upgrading the EMRs to be Ségur certified, the system will include the INS;
    d. Launch a study on the enforceability of security and interoperability standards and strengthen the compliance controls for publicly funded HIS.
    e. Implement a health terminology management center (CGTS[24]) equipped with a multi-terminology server (SMT[25]) to support the semantic structuring of health data;
    f. Provide a national health cyber-surveillance service to report security incidents.
3. **Accelerate the deployment of the core digital services (services for the care actors)**. The idea is to offer a package of services to secure the exchange and the sharing of medical data between the care actors. These services are related to the following:
    a. Fostering the deployment of the DMP as the unique location to store all the data that could be helpful for the patient and the care actors participating in their care journey.
    b. Encouraging the use of the secured messaging system (MSSanté) to secure the exchange of medical data between the care actors.
    c. Proposing an e-prescription service to simplify and secure the prescription workflow from the doctor who prescribes to the pharmacist who dispenses.

[18] La délégation ministérielle du numérique en santé
[19] L'agence du numérique en santé
[20] The Ségur du Numérique en Santé was created in 2021 with the aim of generalizing the fluid and secure sharing of health data between health professionals and with the user for better prevention and better treatment.
[21] https://esante.gouv.fr/produits-services/pro-sante-connect
[22] Cartes de Professionnels de Santé
[23] Identifiant national de santé
[24] Centre de Gestion des Terminologies de Santé
[25] Serveur Multi-Terminologies

d. Developing territorial digital services to coordinate care pathways defined in the e-parcours programs. Figure 11 highlights how this kind of tool should enhance the success of the organizational configuration of care actors. For instance, the e-parcours tools aim to gather the different members of the CPTSs around a shared agenda, so they find an actor who can see the patient rapidly. At the same time, they offer a discussion channel to communicate about the patient with the possibility of building personalized care pathways for the population they are caring about. Those projects are led by the GRADs[26] charged with promoting e-health services.

4. **National deployment of digital health platforms**: intended to allow patient, medical and medico-social actors to find their bearings in reliable and easy-to-access digital spaces:
    a. Develop a Digital health space to enable all residents to access digital health services in a secure and seamless environment. Through the space called "Mon Espace Santé," all the users can manage their medical data and communicate with their care circle.
    b. Offer the care actors the possibility to communicate with the patient.
    c. Create a health data hub to retrieve the collected medical data in a single, secured database to analyze it on a large scale for the population's benefit.

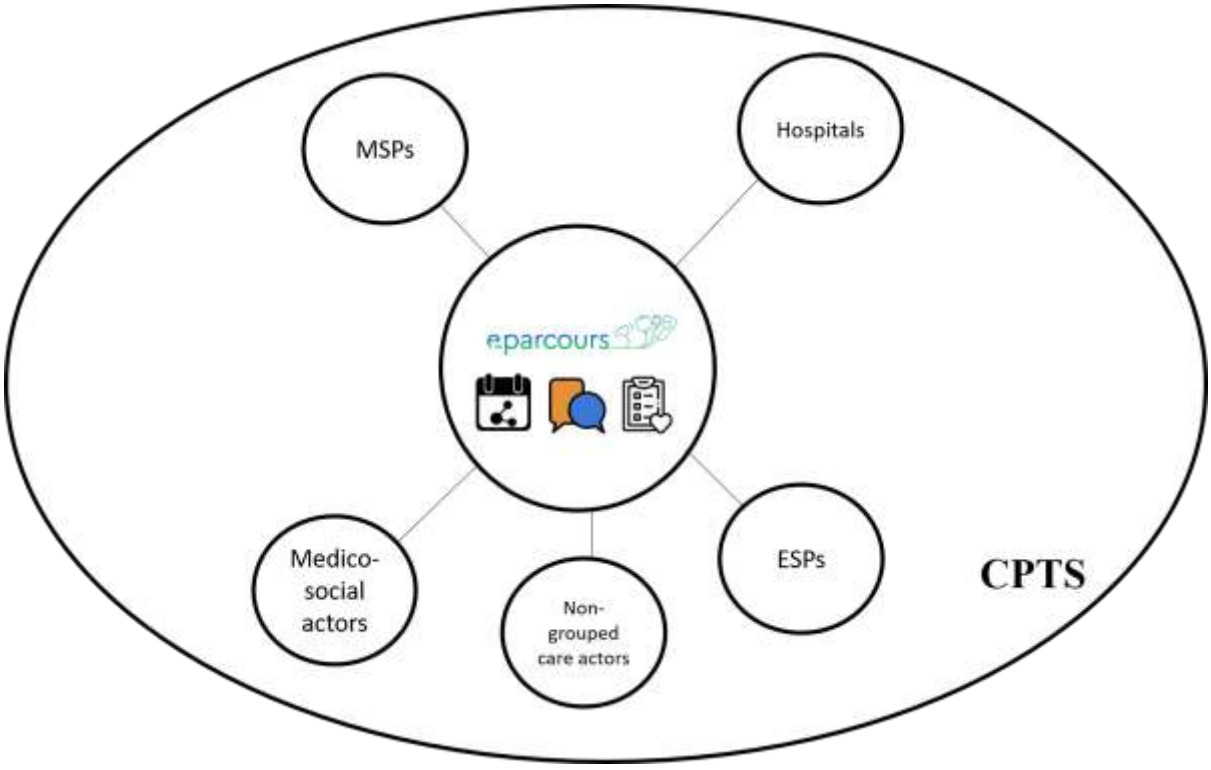


Figure 11 The use of technology to integrate and promote the cooperation between care actors

Despite the efforts made in recent decades, various studies have revealed that the French healthcare system remains compartmentalized, particularly between care actors with private practices (in urban areas) and public practices (provided mainly by hospitals) (Moyal & Fournier, 2022). Those studies show that the focus on digital solutions seems less relevant since the organizational integration model is less effective (Rizoulières, 2021). Regarding the DMP, care actors criticize how documents are organized as a list without any order, making their review

[26] Groupement Régional d'Appui au Développement de la e-Santé (GRADeS)

hard and time-consuming. The DMP also creates additional workloads and ambiguity issues concerning the context of its content (Merliere, 2021). Moreover, when it comes to the different e-parcours tools, studies discussed the problematic integration of the tool into the care actors' practices. The functionalities of these artifacts and how they should enhance care actors' cooperation are not clearly defined. They are often viewed as additional shared medical records with little distinction from the existing DMP. Additionally, their potential as communication tools for emergencies remains unclear (Aubert et al., 2020). Moreover, the definition and implementation of patients' pathways are not standardized across different care settings. Hospitals focus on defining pathways based on specific pathologies due to their specialization in certain medical fields. At the same time, care actors with private practices often consider a more holistic approach that integrates medical and social factors. This disparity in defining patients' pathways can lead to confusion and miscommunication among care actors, ultimately hindering the achievement of integrated care (*ibid*).

3.1.3 Healthcare System Integration in the Aube County

The Aube County is situated in the North-East of France with around 310 161 inhabitants[27]. The care is ensured by 11 public hospitals, 12 private institutions, and about 3820 care actors with private practices (*ibid*). At the same time, the county counts 22 MSPs[28], 3 ESPs[29] , and 2 CPTSs[30].

As indicated above, Aube County represents one of the pioneers' territories experimenting with the population-based approach defined by the FHF. This approach projects to improve the health of a population by coordinating the care actors working in the city and the hospital by focusing on prevention and defining care pathways for categories of patients. It was launched in 2019 in Aube and Sézannais by the Resp'Aube association (Allard, 2019). This association offered the first bricks to create the various CPTS in Aube County. Three significant objectives were set; 1) create a healthcare community gathering outpatient, self-employed, and salaried care actors alongside representatives of public and private health establishments as well as representatives of the medico-social sphere, 2) train and help care actors to apply the clinical programs and benchmarks established nationally for the two first-line target populations (diabetes and heart failure), 3) work with partners to categorize the population for three additional themes: Chronic Obstructive Pulmonary Disease (COPD), elderly and disabled people, and people in precarious situations. Then, once the categories are defined, train the care actors (*ibid*).

However, although those efforts to gather care actors around joint health projects, the various organizations (for instance, the CPTSs) are still working to formulate the health project, define the adherence process, and the way to attribute the different roles to each contributor. Consequently, care actors continue to treat each patient in isolation, focusing on their perspectives and their specialty-related roles.

Alongside creating the CPTSs and the ESPs, the county deployed a technological solution allowing the coordination of care actors to follow patients' pathways. The system, called Parcéo, is promoted by the supervision of the ARS and Pulsy (presenting the regional support group for the development of e-health in the Grand East region). It intends to offer a unique solution (compatible with the care actors' EMRs) to fulfill the needs of the different CPTSs in the Grand

[27] https://www.grand-est.ars.sante.fr/media/31280/download
[28] https://www.grand-est.paps.sante.fr/media/42104/download?inline
[29] https://www.grand-est.paps.sante.fr/media/42102/download?inline
[30] https://solidarites-sante.gouv.fr/systeme-de-sante-et-medico-social/structures-de-soins/les-communautes-professionnelles-territoriales-de-sante-cpts/article/les-cpts-en-grand-est

East region for communication and exchange. The first campaign to present the tool dated to 2020, when Pulsy announced that Parceo would be deployed by the end of 2020 (Pulsy Newsletters, 2020). However, the tool was not launched until Mars 2021 (Pulsy Newsletters, 2022) due to the delays caused by the COVID pandemic. It was not operational until September 2022, with experimentation involving 240 care, medico-social and social actors (Pulsy Newsletters, 2021).

Parcéo is promoted as a "Professional social network and instant messaging service." It offers features that allow the care actors to identify all the care actors of the territory. Moreover, it provides care actors with a professional social network allowing them to exchange around themes relating to good practices, pathologies, or protocols. At the same time, it allows the users to personalize their patients' pathways and share a common agenda, liaison book, and medical record (Pulsy, 2022).

To prepare for our fieldwork, we enrolled in presentation sessions organized by the Public Health and Performance Territorial Pole of the South Champagne Hospitals and Pulsy to inform the care actors about the functioning of Parcéo. Through those sessions, we learned that one of the aims of Parcéo is to act as an automatic fallout of the various produced documents around the patient in one place, which highlights the same confusion raised by (Aubert et al., 2020) about the position of the "e-parcours" tool towards the DMP. We also discovered that pathways coordinators are needed, with ambiguities about who could endorse this responsibility: the patient's assigned physician or the newly created advanced practice nurses. Furthermore, Parcéo aims to provide care actors participating in the same CPTSs with a tool that facilitates patient monitoring and coordination to establish personalized care pathways. However, the effectiveness of Parcéo relies on the prerequisite that care actors involved in the patient's care have been identified, acknowledged, and have collaborated to develop individualized care plans. Nevertheless, as previously emphasized, care actors continue to operate independently, each in his corner, as CPTSs are still in their nascent stage and have yet to establish their strategy or operational framework, which impedes the implementation and utilization of this tool.

Our thesis presents a different approach to improving cooperation among healthcare providers. Rather than solely focusing on team building or technology, we analyze the individual practices of care actors within a patient's care circle. These actors may not have prior knowledge of each other, but they all play a critical role in the patient's care and document their interventions. Within this study, the care circles are examined using a population-based approach to establish them as formal organizational entities, despite their lack of inherent team or group structures. Consequently, throughout this thesis, the inclusive term "care circle" is employed to encompass the various care actors engaged in patient care (Agence De Numérique en Santé, 2020). This terminology choice aligns with their shared recognition of collaborative endeavors and the envisioned manifestation of such collaboration. Accordingly, in this work, we aim to comprehend how these care actors collaborate to provide the best possible care to the patient. Based on this understanding, our objective is to develop tools that align with their practices and enhance the visibility of care circle members to promote their cooperative efforts.

3.2 Method

3.2.1 Data Collection

We applied a qualitative research method, conducting a series of semi-structured interviews. Our study lasted for a period of ten months, from January 2021 to October 2021.

The objective of our work was to explore the process of constructing an overview of the patient's case to inform the design of a technological tool that facilitates its visualization regardless of the data sources used to convey the required information. Consequently, while acknowledging that patients serve as conduits of information between care actors in integrated care (IC) (Chen & Pine, 2014), we focused on the care actors working to define and follow the diabetic patients' care pathways when we recruited participants for our study. Thus, we contacted the South Champagne Hospitals' Public Health and Performance Territorial Pole to reclaim the list of care actors who participated in the information sessions about Parcéo. We also relied on a regional directory to find other care actors treating other pathologies that may be related to diabetes. We sent over sixty emails, and we follow-up those emails with phone calls to give more insight into the purposes of our study.

We were able to schedule 22 semi-structured interviews. Many were rescheduled many times due to the third and the fourth waves of the COVID-19 pandemic and to the different restrictions. Seven interviews were held online using videoconferencing tools (Zooms and Teams). Ten interviewees were employed by various public institutions, nine with an exclusive private practice and three with a hybrid practice (working as employees for public and private institutions and as self-employed actors in the city) (see Table 1). The interviewees' experiences ranged between 6 months and 40 years, and the average duration of the different interviews was 45 minutes. The interviewees were held in nine different places, spread through four cities of Aube County (see Figure 12). All the interviews were audio recorded and transcribed.

Figure 12 The location map of the interviewees

During those interviews, we asked about the care actors' practices and how they managed to get an overview of each patient's case to ensure cooperation with the other actors to allow continuity of care. We included questions about a) The data that they document about the patient; b) the

type of artifacts they use to keep that data; c) The data they share, the channel used for this sharing as well as the moments when they chose to share; and d) What they receive from the other actors who treat the same patient. We used the results of our data analysis, based on a qualitative data analysis approach, to guide further data collection. Thus, we adapted our protocol to include questions about i) their perception of the data they receive, ii) the situations when they needed further details, and iii) their ways to gather that data.

3.2.2 Data Analysis

We applied the open coding technique from the grounded theory approach (Corbin & Strauss, 1990) to analyze the qualitative data (the transcribed interviews) collected during our fieldwork (Figure 13). We performed multiple rounds of coding. The results of each round were discussed with this doctoral work's primary supervisor.

Table 1 The list of interviewees according to their sectors and workplaces

Sector	Workplace/location		Position
Salaried	French Mutual Health Center (a multi-professional health center) – Troyes		Endocrinologist_1
			Nurse_1
			Dietician_1
	Troyes Hospital Center – Troyes	Endocrinology department	Endocrinologist_2
			Endocrinologist_3
			Nurse_2
		Emergency department	Emergency_physician
		Internal Medicine and Infectious Diseases department	Specialist
	Public Mental Health Institution of Aube – Brienne-le-Château		GP_1
	Aube-Marne Hospital Group - Romilly-sur-Seine site		GP_2
Private practice	S.O.S Médecin – Troyes		GP_3
	Private practice – Troyes		GP_4
			Endocrinologist_4
			Endocrinologist_5
			Pharmacist
			Podiatrist_1
	ESP de saint julien les villas		Lab_doctor

		Nurse_3
		physiotherapist
Hybrid practice	Private practice / CHT –Troyes	Podiatrist_2
	Private practice - Troyes / Aube Private Clinic - Troyes / Aube-Marne Hospital Group - Romilly-sur-Seine site	Dietician_2
	Private practice - Troyes / Aube Private Clinic - Troyes / Private clinic Montier la Celle – Troyes	Dietician_3

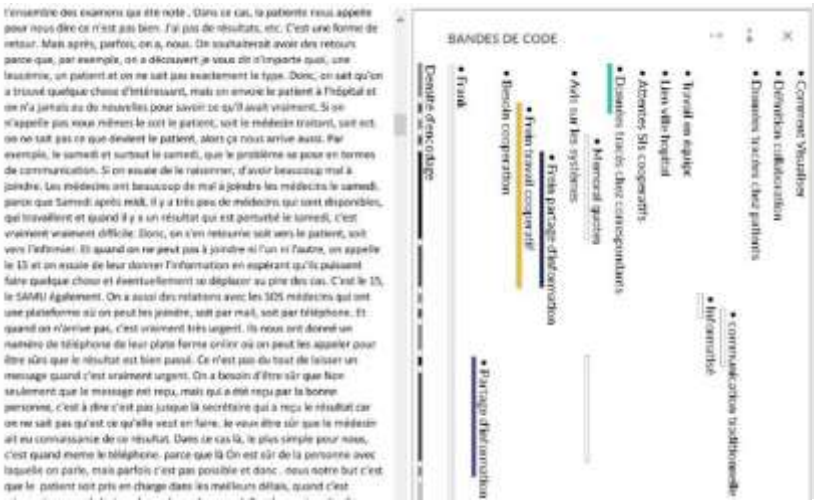


Figure 13 Coding the transcribed interviews (with NVivo)

In the first round (Figure 14), we investigated how care actors construct a patient's case overview. Therefore, we sought strategies to share medical data, communicate about the patient, and build and maintain the overview. We have established a set of themes to describe our study's key concepts. One of these themes is "systematic document sharing," which denotes the practice of systematically sharing documents created by care providers following each patient appointment. Another theme is "permanent communication," which emphasizes the ongoing communication between care providers about the patient. Lastly, we have the theme of "creating a situated overview," which refers to achieving a personal overview that allows each care actor to treat the patient from their, role, perspective and the patients' situation.

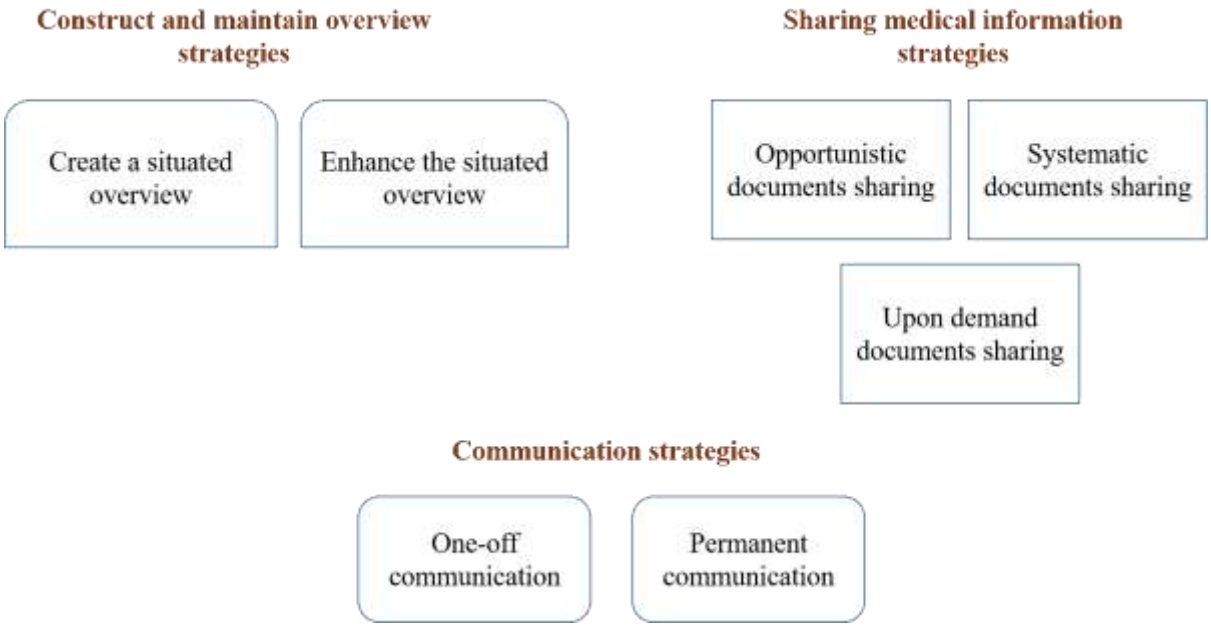


Figure 14 Examples of the codes identified during the first round

In the second round of coding (Figure 15), we accomplished an axial coding where we identified relationships between the strategies to create and maintain the overview with the strategy to share medical data and communicate. For instance, creating the situated overview is based on "opportunistic document sharing" and capitalizes on "one-off communication."

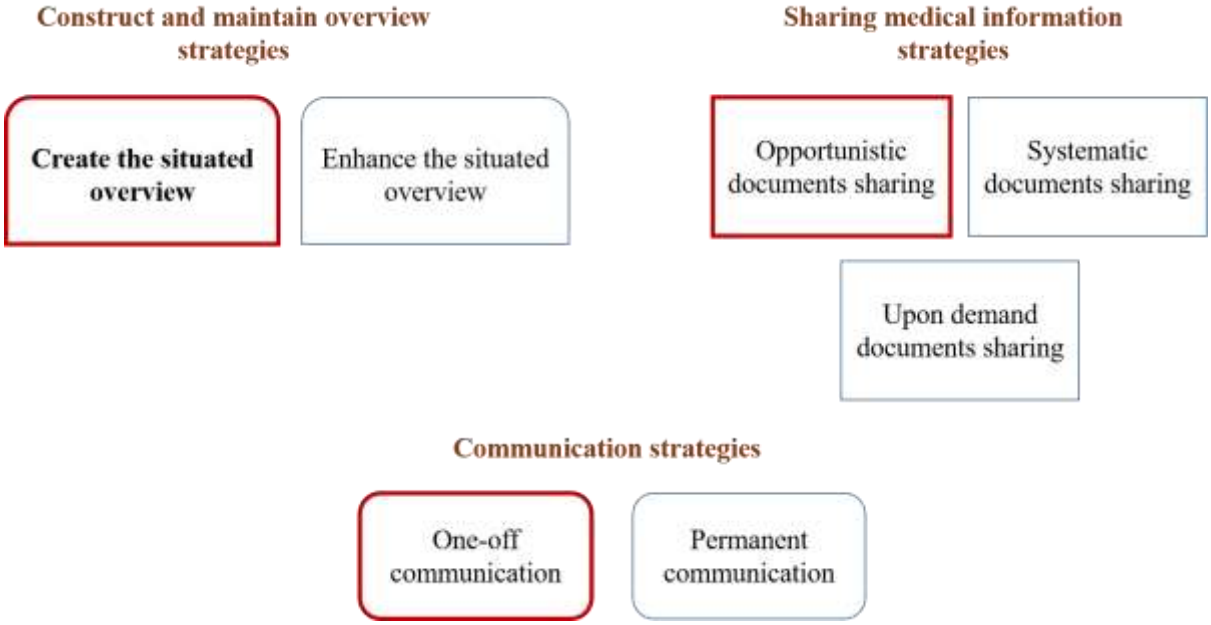


Figure 15 An illustration of the type of relationship (in red) between the identified codes

Next, in the selective coding phase, we elected "construct and maintain an overview" as the central theme and used it to organize the other categories. This analysis allowed us to comprehend how care actors cooperate so that each gets a situated overview of a patient's case, underlining the pivotal factors that foster or impede this elaboration of the overview. For instance, we discovered that to "create and maintain a situated overview," "opportunistic documents' sharing" is a key factor and that the failure to hold a "one-off communication" may hinder this creation.

3.3 Results

Within the context of IC, inter-professional and inter-organizational cooperation are essential to guarantee the coherence of the delivered care. The fragmentation and the variation of roles and goals challenge this cooperation. However, care actors do their best to share documents and communicate with the other care actors to build an overview of patients' cases. In this section, we present the challenges hindering cooperation within IC, how care actors encounter them to create the overview they need of a patient's case, and the issues they face when building this overview.

3.3.1 Obstacles to Effective Cooperation and Coordination in Integrated Care Pathways

Integrated care pathways aim to categorize the population and determine the type of care required for each patient, including the steps and relevant care providers. However, several challenges hinder their implementation. Firstly, identifying patients who should be included in the early stages of their disease to focus on prevention and avoid serious complications needs to be clarified. Secondly, patients must have a nominated assigned physician to be enrolled in the program. Still, a large percentage of the population needs an assigned physician, which excludes them from the program. Thirdly, the definition and coordination of care pathways for a specific population category are unclear to care actors.

> "*No one can enroll in a care pathway unless they have an assigned physician. Therefore, we have a whole category of the population that is excluded. Those people do not exist for the system [healthcare system]. They only exist in emergency structures during emergencies or in the hospital when there are complications, but otherwise, they do not exist. Already to include them, we have to identify them and their issues. Yet, when you do not have a tracking system, we cannot identify the people to include or implement any prevention approach. That is by far a serious challenge. [...] When creating a coordinated care pathway, it is necessary to specify who can define it, coordinate and follow it. Yet, the system lacks specifications about all of that. We should really consider writing that information first before setting up any program*" **Emergency_physician**

Therefore, with the failure of those processes to determine a common way of working, care actors with private practice and salaried from hospitals continue to work in an isolated way.

> "*We work separately. Each one of us works in its corner, in isolation. This is a serious weakness that disturbs us. This is a big defect threatening the patient's safety. It is a real problem because ignoring the necessity to work together generally results in patients' hospitalization, which fills the emergency room that struggles to handle all the cases*." **Nurse_3**

Moreover, care actors tend to work in silos, with private actors on the one hand and public ones on the other. Therefore, competition and concurrence between the various sectors have arisen.

> "*The care actors working in hospitals have a slightly different status, so they prefer if we can say, to speak and work with hospital employees rather than with the city practitioners. So generally, the city refers to the city, and the hospital refers to the hospital, which is normal [....] Also, we cannot hide it, but there is also a certain competition and a certain, we are not going to say a forfeiture is not the word, but each sector wants to prove its efficiency*." **Lab_doctor**

In this context, it becomes very difficult to share data and to communicate among the different care actors who are, on the contrary, supposed to cooperate so that their patients follow the dedicated care pathways

3.3.1.1 Fragmentation of the Medical Data

The compartmentalization and competition between the different care actors can affect the decision of the patient to inform the care actors around them about their care circle. Consequently, care actors can lack visibility of the patient's case and miss data depicting the different care episodes treated by other actors.

> "*We had a patient who had been discharged from the hospital. Then, she was followed here [the multi-professional health center] and in the hospital to track her progress. The patient did not dare to tell the hospital she was being followed here, so we did not have any information from them. We lacked a common record that could have informed us about their actions. So, all we could do is keep communicating with the people we know there to seek information and details*." **Nurse_1**

This may result in gaps in the patient's treatments or redundancies in the actions undertaken by the actors, like, for instance, performing exams that were already performed before, which consequently increased care costs.

> "*Sometimes I have patients who tell me: "I had a blood test 15 days ago." Therefore, I call the labs to find their results. However, sometimes we fail to find this information. Then, we redo the exams. Many exams are done several times because the patient will have several doctors, but he is imprecise [about the nature of the exams he made] or cannot provide his results or the actors who prescribed them. It is a real issue because many patients cannot and do not know what to tell us. Yet, I believe that having all the elements about the patient could ease our work and reduce costs because we would do fewer additional examinations.*" **GP_1**

Moreover, while the DMP was defined and deployed as a system aiming at avoiding this data fragmentation, the care actors raised questions about its usability and the need to define new roles related to data management.

> "*The DMP has been launched, but we encountered several issues. I mean, it takes time to fill in the data. In theory, the assigned physician is the one who must enter the information because they are the one managing the patient's case. Afterward, they can define the various care actors who can participate. However, I think we do not have the time to feed it due to our workload. Maybe we lack staff in charge of the task of entering patient data. In fact, some people with diabetes have been followed for decades; their records encompass an extensive quantity of documents. […] We may have patients who have no history. Then, it will take no time to feed their records. However, for all the patients with long histories, for some that may go up to 50 years back, it becomes difficult to upload all their information. Therefore, we must delegate people who can take care of this task. Otherwise, it will never be done [feeding the DMP].*" **Endocrinologist_1**

In addition, when integrating patient data into the system, care actors faced challenges in accessing the data due to interoperability issues between local EMRs and the centralized DMP. As a result, the lack of communication tools between these systems hindered effective access to stored data.

> "*When we want to access what is already stored there [in the DMP], we discover that we do not have the necessary tools to open them [the data] when we want to. There is a real problem with retrieving all the data to synthesize when needed. It is one of the pitfalls of the current system [the DMP], which is deficient and leads to redundant examinations […]. It is a real shame.*" **Endocrinologist_1**

As a result, care actors perceive the DMP as an additional burden that complicates their workload and does not align with their existing tools and workflows, rendering it less useful in practice.

> "*Those systems [the centralized one] turned out to be a big problem because they are very exhaustive, I would say, way too much exhaustive. After all, care actors do not have much time to review this quantity of data. As I mentioned earlier, care actors have different software; each has personal and professional software. Then, we are asked to use the DMP as a shared medical record, which adds*

another tool to what we usually use, which generates another administrative work. Moreover, it is not always correlated to what we saved, so we are confused about which information is more accurate." **Podiatrist_2**

Additionally, each care actor prioritizes organizing and maintaining the data relevant to their specific role in providing care. However, the DMP is intended to serve as a platform to store all documents generated by the various care actors involved in the patient's case, which can complicate searching and navigating within the medical record.

"*It changes how we work and overwhelms us with data we do not need. It is as if we had a library that we organized according to our needs and used to keep the books we wanted to read. Then, suddenly, we were asked to move our books to a larger library. Then, when we want to find a recipe book, we need to prepare something, but we cannot find it. We must browse the entire library to find it. Maybe it will take hours to find it, whereas we will find it right away with our own organization, our own system*." **Emergency_physician**

The fragmentation of medical data across different EMRs and the limited access provided by the national DMP initiative hinder care actors from finding the information they need to obtain a comprehensive overview of a patient's case. As a result, they often resort to workarounds, such as contacting their colleagues to request missing data. However, these workarounds come with their own set of challenges.

3.3.1.2 Impeding Communication

Communication between care actors can help ensure that critical medical data is not missed and that a complete understanding of the patient's case is achieved.

"*For me, collaboration is the exchange around a patient. Not always, not necessarily all the time, but occasionally. For me, this is what collaboration is all about. It is an occasional exchange.*" **Podiatrist_2**

Thus, when care actors need data about a particular care episode, they contact their possible personal connections to seek the data they lack. For instance, actors working in the private sector contact people they know in public institutions to coordinate their work and allow integrated care.

"*I am lucky enough to be from the same generation as the two podiatrists who still practice at Troyes Hospital Center at the Diabetes Ambulatory Care Unit. Therefore, they are actors that I know well, and I have their contact details so I can reach them when I need any information about the patient we see together [referring to the patient's treatment in her office and at the hospital].*" **Podiatrist_1**

However, relying on communication to bridge the gap caused by the compartmentalization and fragmentation of medical data is challenging. Care actors with diverse backgrounds and roles face hurdles related to differences in perception and culture. For instance, physicians may assume they have the authority to lead and manage a patient's care over nurses and pharmacists, creating power dynamics that can hinder effective communication.

"*When we wanted to create the ESP*[31]*, we often had physicians in front of us arguing that they needed to be the bosses. They argued that they are doctors, they are more qualified, they had six, seven, or eight years of studies and even more for the specialists, and thus they argued that they need to be at the top of the pyramid*." **Nurse_3**

This stratification may lead to conflicts and contradictions in the patient's treatment, dampening the continuity of care. Additionally, medical secrecy may limit access to data through

[31] For Equipe de Soin Primaire in french : primary care team

communication, requiring paramedics to negotiate with medical care actors to access necessary data and explain why they need it.

> *"When we need information about the patient, we call their assigned physician, and we try to negotiate with them if they agree to give us the diagnosis, explaining that accessing this information may ease the reading of the cells."* **Lab_doctor**

Moreover, while the government aimed to launch e-parcours systems aspiring to bring together the care actors involved in the integrated care pathways from all backgrounds to foster communication and sharing, it confronted deployment and appropriation issues. In fact, the integrated care pathways need to be collectively defined beforehand to be integrated into the system, allowing the care actors to apply them and then cooperate in following the care pathways.

> "*To start, we should write things down and link them to a population-based approach. We need to define the integrated care pathways that need to be co-constructed and for which we can use digital tools to ease cooperation within the pathway. Once you have defined the integrated care pathways, submit them to the local community managing them. Then, they can say that Mr. Durand, who is overweight, who smokes, and who is 40 years old, needs to see the physiotherapist, he needs to practice more sports, he must consult a dietician at the medical center, he needs to see the physiotherapist and maybe the nurse twice a year, and the doctor once a year. After that, we create a shared record for him, in which we can submit all this medical data. And through this digital tool, we can cooperate with the different care actors who participate in this program, share the agenda, send alerts, and exchange […]. The other way around [creating the team within the tool then creating the integrated care pathway] will never work."* **Emergency_physician**

To summarize, while managing patients with long, complex cases require cooperation among various actors so that they can each get an overview of patients' case, care actors face many hurdles. They struggle to gather fragmented data within the different EMRs. Thus, to overcome this fragmentation, care actors rely on creating, sharing, and searching for medical documents to elaborate a situated overview of the patient's case, which allows them to maintain an awareness of the situation based on their perspective, role, and need. Achieving this situated overview allows them to get the sufficient data they need for their activities and guarantees the continuity and the coherence of the care.

3.3.2 Care Actors Practices to Build and Use Overviews of Patients' Cases

Considering a patient's journey through various care settings, data from each encounter is spread across the different documents generated by different care actors. As a result, care actors have developed unique approaches to create a situated overview of the patient's case, essential to fulfilling their respective roles in delivering care and ensuring coherence with the patient's overall treatment plan. Despite the individual nature of these practices, there are commonalities in terms of 1) how documents are collected, selected, and organized to build a situated overview of the patient's case, 2) the use of communication to enhance this overview, and 3) the strategies for using this overview to ensure optimal care. In the following sub-sections, we describe these shared practices in more detail.

3.3.2.1 Gathering, Selecting, and Organizing Documents

Care actors begin shaping an overview of the patient's case from the initial encounter by gathering, selecting, saving, and organizing relevant documents. These may include documents sent by colleagues referring the patients, those requested during medical appointments, and those brought by patients themselves. Referral letters and prescriptions are often mandatory to book appointments, as they provide information on the reason for the visit and the requested treatment. For example, a diabetologist may be asked to treat a patient's diabetes imbalance, or a

lab doctor may receive a prescription for blood tests to diagnose a particular problem. Referral letters can also provide insight into the patient's medical history in some cases.

> "*When patients call to fix an appointment, the assistant will inform them that they absolutely must have a referral letter, depicting their history and problematic, that we need to see to understand their cases and decide if we can manage to see them*." **Specialist**

However, there is no consensus on the practical way to write referral letters, and some critics have raised concerns about the quantity and quality of the information provided. As a result, care actors tend to attach abstracts of all the documents they store within their digital records, including their notes, to the referral letters to ensure they provide sufficient information to their correspondents.

> "*Some doctors will give you a very, very detailed letter, i.e., all the patient's medical history. Others will use their digital medical record to generate a summary they attach to the letter. Thus, we will have the family, personal, surgical, and medical history. In addition, we will have everything related to the pathology for which we see the patient with their results, etc. Sometimes it is unbelievably detailed. Sometimes too much. I mean, sometimes, you have a summary of all the digital records, the details of why he was seen, and what they have done during all the visits for several months or years ago.*" **Endocrinologist_4**

However, as illustrated above, handing overabundant letters may lead to confusion, obscuring critical concerns. Consequently, care actors may focus on unexpected problems.

> "*I keep telling myself that if I refer my patients with a not precise letter, the specialists will not have all the information they need. Yet, they will not read everything if the letter is too elaborate. Sometimes this is what happens. We can see that they have not read everything because they answer vaguely, missing the main point.*" **GP_1**

Alongside the referrals and the abstracts that care actors may receive with a patient during their first encounter, care actors create their situated overview of the patient's case by including the documents that complete the data mentioned in the referral. For so doing, some actors ask patients to bring various documents that provide details about their past care episodes, such as the last lab results and previous reports.

> "*Our medical assistant knows that when she makes an appointment, she needs to check if the patient is one of our old patients. Then, if they are new patients, she tells them that we do not know them; they are not in our system, and we do not access their medical records. Therefore, she asks them to come with their reports, latest lab results, and any medical synthesis they have*." **GP_4**

In contrast, others count on the patients to bring any documents they may consider essential to describe their case. Then, during the encounter, they browse them and decide whether to keep copies of those documents within their overview.

> "*When patients come in for consultations, we usually ask them to bring along some relevant documents. However, most patients tend to bring in more documents than we requested. In such cases, we usually skim through the documents rapidly, trying to identify any crucial data we may want to keep for addressing potential issues in the future.*" **Specialist**

However, in some cases, care actors may lack access to additional data. When care actors receive a patient without referrals or when the patient is unable to provide any details about their medical history, they may work to collect different documents related to the patient to create an overview. In such cases, they may have to contact various correspondents involved in the patient's care to obtain those documents and details.

> "*Our patients are generally unable to tell their stories [...]; the referral documents remain with the specialists because they need to focus on treating the psychiatric pathology [Since the patient was*

accepted in the facility due to a psychiatric issue]. Therefore, when we [the general practitioner of the mental hospital treating other medical problems] need to have more information, we call the emergency department, we call the patient's assigned physician; when we manage to have them on the phone, we usually call the pharmacy for the treatment, the lab to get the results of the labs..." **GP_1**

Once care actors have gathered and organized the necessary documents to build their situated overview, they make a diagnosis and prescribe treatments for the patient. Afterward, they record a summary of the encounter, including their observations, diagnosis, and treatments prescribed. This summary is stored in their digital records to keep track of the case for future encounters with the patient. Additionally, they may write summaries to inform other correspondents about the patient's problems, diagnosis, and suggested care plan. These summaries allow for efficient communication and coordination among the care actors involved in the patient's case.

"With diabetologists, systematically, on their prescriptions, they put the patient's history in a few lines and below, they prescribe very well the specific sessions we need to provide to take care of diabetic patients. For example, a patient with a Grade 2, which means that he has neuropathy or arteriopathy, will be entitled to four sessions in the year or one per quarter [...] So, it is very, very well described informing us about the context of our work." **Podiatrist_1**

Nevertheless, not all documents produced by the various care actors are automatically sent to all other care actors involved in the patient's care. The patient's assigned physician will receive all the documents generated during the encounters with other care actors. However, referring actors will only receive a follow-up synthesis if the care actor producing the document deem it necessary or if the patient's assigned physician believes it is essential to share the information. This selective approach aims to avoid overloading the care actors with unnecessary information and to ensure patient data confidentiality.

"In the medical field, collaboration is sharing information; it is looking for and sharing information to treat the patient better. However, we do that just when there is a need and when there is a problem. When everything is fine, it does not happen," **Podiatrist_1**

The previous verbatim explains how sharing and seeking medical documents are typically triggered when the situation demands it. Accordingly, when the patient's condition is stable, care actors utilize their created documents to maintain their situated overview. Thus, they do not share or seek documents from the other actors involved in the patient's care. In particular, paramedics tend to share documents informing correspondents about their intervention only after the beginning of new events or to inform them about the care plan's progress and evolution. For instance, therapeutic education nurses tend to write to the assigned physicians on two occasions. First, to inform them about the start of a new therapeutic education program, and second, once they complete the program to outline the actions made. Likewise, dieticians and physiotherapists write to inform and update care actors about their intervention only if requested.

"*We never make systematic reports except when the assigned physician asks. For example, last week, I had a doctor on the phone who asked me to care for one of his patients because he has a minor intervertebral disorder. Therefore, he gave me a precise diagnosis of the problem and asked me to check that out because the patient was in horrible pain. Therefore, I quickly fixed an appointment with the patient. I had the assigned physician on the phone at 11 a.m. and 2 p.m. I was taking care of the patient. Then, I prepared an explanatory report that I sent to the assigned physician afterward.*" **physiotherapist**

However, when care actors assess that their findings and treatment plans must be considered before further care, they may also inform the other actors around the patient. For instance, an endocrinologist can write to the patient's assigned physician as well as their cardiologist,

nephrologist, or ophthalmologist to inform them about the diabetic's situation and the recent decisions which may interfere with the care they are delivering to this patient.

> '*We write to the correspondents who can be private actors or from the hospital. Each patient will have an assigned physician and a multitude of specialists to whom we must address, a private pulmonologist or a pulmonologist working in the hospital, a cardiologist, etc. There are multitudes of correspondents to whom we send our summaries each time depending on each patient's case.*" **Endocrinologist_1**

Afterward, each time they meet the patient, each care actor updates and refreshes the overview they have created about that patient's case, which also updates the content of the record they create to maintain this overview.

As we mentioned earlier, to maintain their situated overview, care actors rely on storing the various documents they selected in one place, which can be either paper-based or digitalized. This record then includes every document they write to keep track of their activities, receive, select from what the patient brought, or search for from the other correspondent.

> "*We write our synthesis on the software we use. Similarly, we record the synthesis we send to our correspondents on the same software, and we keep that for later use. Likewise, we store the specialists' answers that arrive on APICRYPT [encrypted messaging service] on our records, so we have everything at hand. And if the medical assistant receives them [the other correspondents' answers or documents] by post mail, she scans everything, and we can check them later when needed*." **GP_4**

Saving all the documents related to a patient in their records (paper or computer-based) allows the care actors to monitor the progress of a patient's case from their specialty's perspective. It permits identifying the other care episodes treated elsewhere. This way, they can detect any existing links between the various issues to make a better diagnosis.

> "*In fact, [to work], we need to have access to all the data [about the patient]. Therefore, Crossway [local EMR] is the tool I use, as well as Mrs. Endocrinologist_1 (who works in the same health center) and the general practitioners working in our site in Sainte-Savine [a small town nearby] because we also have patients from Saint-Savine followed by GPs there. Therefore, we have access to the patients' information generated by all those people. At the same time, all the documents, for example, referral letters from doctors and the lab results, and everything we receive [from outside the health center] are scanned in Crossway to access everything*." **Nurse_2.**

Indeed, getting summaries depicting all the events around the patient (not only the summaries they have written) allows care actors to get a better overview to ensure the consistency of care.

> "*The collaboration is to have access to some parts of the patient's medical record, the ability to have access to the different letters, summaries, and prescriptions of people seeing the patient help us a lot to work together*." **Endocrinologist_3**

Moreover, care actors tend to group semantically tied documents within their records to ease the use and navigation through their situated overview. For instance, they put referral letters together with their answers to keep track of the context of each document.

> "*We record our letters on our software, and then when the specialist's answer arrives on APICRYPT or via mail, the assistant puts it directly in the same place as my letter so I can find it, and everything will be available so I can review them at the same time."* **GP_4**

However, in many cases, the care actors lack context information about the patient's situation, primarily when the patient cannot provide more details or explanations. Therefore, they communicate with patients (when possible), relatives, and other correspondents to extend the data they get from the documents they include within their overview.

3.3.2.2 Communicating to Enhance the Created Overview

During medical consultations, care actors communicate with patients, their informal caregivers, and relatives to clarify and contextualize the data inscribed within the patient's medical documents. They also communicate with their peers to obtain the medical documents they lack. However, the ease of carrying out this task depends on the care actors' information about their correspondents. Accessing the documents generated by other care actors helps identify their names, addresses, and specialties. Additionally, care actors rely on patients and their relatives to provide information about other care actors involved in the patient's care. However, if patients have moved between cities, tracking their care pathways becomes even more complicated.

> "*We see patients that consulted multiple care actors in Paris and do not have copies of their documents. It is a real problem; we lack a medical record that is carried out by the patient and which they would manage to bring to their different consultations [...]. This is one of the pitfalls of the current system [health system], which is really failing and leading to redundant exams*." **Endocrinologist_1**

In this case, care actors start by checking if the patient has an assigned physician, considered the patient's records gatekeeper, and to whom all the correspondents generally address their reports and results. Then, once they identify this person, they request documents or clarifications about the patient's history and current situation before turning to the other specialists around the patient.

> "*I usually begin by contacting the assigned physician as disturbing the specialists may not be appropriate. Typically, I call the assigned physician to see if they have the information we are searching for..*" **Lab_doctor**

But, as we pointed out earlier, access to the documents is only sometimes guaranteed for all the actors around the patient. It requires consideration of the role and the position of the care actor requesting the documents to define what they can access. For instance, laboratory doctors must negotiate to request a diagnosis that helps them interpret their blood tests.

> "*Generally, I call the assigned physicians. I ask them if they agree to inform me about the diagnosis, especially in hematology. Knowing their patients' pathology makes it easier to analyze the results. When we examine blood cells, it is easier for us, if we already know the diagnosis, if the diagnosis has already been made, it will be easier, to know what to look for, than when we have no information.*" **Lab_doctor**

Moreover, care actors sometimes need more context of the data they receive in documents and thus need help to use it. This may occur when they send the patient a detailed referral letter and receive answers that do not respond to their initial request. In this case, communicating is a solution.

> "*It [the problem concerning the vague response of the correspondents] also happens to me when we refer a patient to a specialist. We will give some details. Then the patient returns with an answer, and we can see that our correspondent did not get what we wanted. Then we wish we had just a moment to exchange with each other. That would be so beneficial to contextualize everything and explain the problems.*" **GP_1**

Communication enables care actors to share the necessary documents to complete the overview they are building. They can discuss which documents are relevant to their current problem and which care actors have those documents. By communicating about the necessary documents, care actors can avoid wasting time searching for irrelevant data and focus on finding the missing pieces. Communication also allows care actors to update each other about the patient's health status, the outcomes of their treatments, and the changes in their care plans, ensuring the continuity and coherence of care. Finally, communication allows care actors to coordinate their

actions and ensure they work towards the same goals, reducing the risk of conflicts and contradictions in the patient's treatment.

> "*When I talk with psychologists, we sometimes have trouble crosschecking our information because we realize that patients, for example, when they want to have surgery [bariatric surgery], they have a precise idea in mind, and they know what they need to avoid saying [so that the surgery is accepted]. Accordingly, they will give me some information and others to the psychologist. However, we can easily identify that because we crosscheck the information we have from the patient, and we can find out if they do not fit. So, checking the story we build about the patient with others is very important.*" **Dietician_3**

Moreover, while documents are generally used to refer patients and are saved to maintain the overview created around the patient, a direct exchange can be a fast way to inform care actors to ask for a speedy intervention or to highlight an issue that was not considered beforehand, and that may relate to a current situation.

> *"I have a patient with high blood pressure levels who went to see a preventive doctor. It turns out that the patient told the doctor [the preventive doctor] that I was the assigned physician. Following their encounter, the preventive doctor requested a Tele-appraisal consultation with a cardiologist from Nancy; they did the electro and found ventricular hypertrophy. Therefore, they decided it was important to send the patient back to the assigned physician, me, to start treating his blood pressure. And I looked [in the medical record] and noticed that I had not seen him for four years.*" **GP_4**

The previous vignette highlighted how communication was mobilized to discuss the patient issue between two actors who judged it essential to alert the patient's assigned physician. Thus, the emerging communication between them and the assigned physician gave information about the situation of a patient whom the assigned physician had not seen for a lengthy period. Therefore, they could readjust their overview and update the record they create to maintain this overview with the new documents pointing to the recent problems and define the actions needed to be taken to treat the patient. Indeed, direct communication is assessed as the practical way to alert the other care actors during emergencies. Moreover, having a synchronous exchange with the concerned care actors asserts that the message that the care actors want to convey is well received by the person who is required to take critical actions.

> "*When there is an emergency, I inform the patient that they must seek treatment ... and I call their doctor. When I have the practitioner on the phone, the reaction is immediate; they may say [the correspondent] yes, I can take them [the patient] right away, or I cannot take care of them right away, tell them to come tomorrow so the next day. It is good to know what to do immediately. Or they may say, look, if you think it's too urgent, send them to the hospital*." **Podiatrist_1**

Care actors create a situated overview of the patient's case by gathering medical documents directly from the patient, receiving documents from peers, and searching for additional ones. Communication is crucial in completing this overview and enhancing the care actors' understanding of the patient's case. However, the number of documents in the patient's record can become overwhelming, leading to different strategies to review and navigate the record productively to build a fast overview.

3.3.2.3 Strategies for Navigating Situated Overview

The strategy applied to review and navigate the created overview depends on the different situations, emerging issues, problems, and the various interactions among care actors and documents. In the following, we highlight three strategies for navigating the situated overview: Chronological, problem-based, and interaction-based.

a. Chronological Navigation

Reviewing documents chronologically is one of the strategies care actors use to navigate their overview. This strategy is particularly useful when they encounter the patient for the first time or during routine follow-up consultations. For example, in the case of an emergency, the ambulance attendant is required to bring the patient's latest prescription, depicting their current treatment and any recent synopses made by the assigned physician and the various specialists treating them, which highlights the events occurring in their trajectory.

> "*The ambulance's attendant must bring back [to the emergency department when they transport the patient] the patient's last prescription, lab results, the liaison book if this one is used in the patient's house, and if the assigned physician or the specialists have sent letters, they must bring them back too. After that, we'll look in the hospital records if we need to go back in time to find more information about their antecedents."* **Emergency_physician**

When seeing a patient for the first time, care actors often start by reviewing the most recent documents, even if the patient brings in a large copy of their medical records created by other actors, which may be in print or digital form. Reviewing recent documents helps care actors understand the patient's most recent care episodes, which can provide context for the current issues alongside the referral letter. They will then consult other documents as needed, depending on their specific needs for building the patient's overview.

> "*New patients always come with huge records containing many, many documents. Some GPs, before retirement, print the entire medical record and hand that printed version to the patient. Others store all that they have on a USB stick. Then, when we receive the patient, we need to review all they brought to continue their treatments. It takes a lot of time, especially for patients with comorbidity who were followed over a long period. In this case, we reviewed what the specialists have written recently. This will allow us to gain insight into the different pathologies, treatments, surgeries, and any red-flagged information we need to consider. Then, when needed, we check back in time to get more details."* **GP_4**

Then, during follow-up meetings, care actors check the last summary they wrote to recall the previous issues they treated. They discuss with the patient to identify any new care episodes. Finally, they check the recent letters, results, and summaries they have received, alongside the ones the patient brought, to complete their understanding of the patient's case. This strategy allows them to navigate the record efficiently and avoid redundancy while ensuring that they have access to all relevant medical documents.

> "*Through the discussion with the patient, we ask them what has happened since the last time [the previous encounter]. If they tell us: "I went to the ED for such a problem, or I was hospitalized, or I saw a specialist," we generally have letters coming from the actors involved informing us since we are the assigned physician of the patient, stored within our systems, so we check them to see what happened*" **GP_4**

To summarize, opting for chronological navigation helps care actors review the various events in the patient trajectory in reverse chronological order. Therefore, they can spot the recent issues that may relate to the current one and then read back in time to understand more about the history and the related antecedents.

b. Problem-based Navigation

In this strategy, they identify the current problem they need to address and search for the related documents, regardless of their chronological order. For example, if a patient suffers from a particular symptom, care actors would focus on finding documents related to that symptom, even if they were not the most recent. This strategy allows care actors to quickly find the information

they need to address the current issue and avoid wasting time sifting through irrelevant documents.

> "*Relying on recent documents is not always sufficient; for example, if we have to treat a patient having trouble breathing at home, we check his recent cardiology report saying everything is OK at the cardiac level. Then, if suddenly the patient loses consciousness, we know that the recent documents may not answer, and we should look elsewhere."* **GP_3**

Thus, when care actors encounter new issues or problems related to a patient's case, they use their maintained records to search for relevant documents. They review their stored documents to see if any answer their current questions. If they do not have the necessary documents, they will search for them and add them to the record to keep the overview of the patient's case up-to-date.

> "*I have seen a patient who took metformin [treatment for diabetic people] for ten years and then switched to insulin for the last two years. I asked about the reason, but he did not know why. Therefore, I have been wondering what happened then and from where that came. Therefore, I wanted to find a little recap about the patient's trajectory, the date of the first prescription, some information about the evolution of their blood sugar levels, and if they encountered difficulties stabilizing it. Having the documents detailing this problem is of great help because we assume something happened, whether the person has suddenly regained a lot of weight or, on the contrary, he may have lost a lot of it. Again, that means there was a slightly disturbing event, an accident, or a depression that can somehow interfere with the treatment or the beneficial effects of the treatments. We need to have that information to offer the best support*" **Dietician_2**

Furthermore, care actors also review documents generated by other actors who treat similar pathologies and issues. For example, suggesting bariatric surgery as a solution for obesity may require input and validation from other care actors, such as a psychologist, a gastroenterologist, and a cardiologist. Therefore, care actors search for and review relevant documents generated by their peers to gain insights, compare diagnoses and treatments, and ensure coherence in the overall care plan.

> "*The surgeons [with whom they cooperate to treat a diabetic patient who suffers from obesity] need to consider the different perspectives. In fact, there are some patients that we may judge as suitable for this type of surgery [bariatric surgery]. But then, we need to check the reports made by the cardiologist, the psychologist, and the gastroenterologist. After that, they may discover that this type of surgery seems less suitable for treating their problems. Thus, they gave me all this information, and it became my duty to find the best plan on the dietary level to get the patient in line*" **Dietician_2**

Care actors require more than chronological navigation to treat problems, as some relevant documents may not be recent. Therefore, they identify relevant actors and documents to respond promptly to new situations. Communication with patients and other correspondents is often necessary to locate the required information and make decisions.

c. Interaction-based Navigation

Interaction is crucial for guiding care actors to search for documents describing a similar issue. It also helps them discover and identify other documents that provide valuable information. Through interaction and communication with patients and other correspondents, care actors can locate suitable sources of information and make informed decisions.

Communication enables care actors to point to medical documents not initially considered, thus improving their situated overview. For example, an informal conversation between a specialist and a nurse allows the nurse to discover previously overlooked documents and provide a more comprehensive understanding of the patient's case.

"*Generally, the patient is asked to bring all their previous documents before they are hospitalized. In fact, this is what I have done with a patient the last time. I checked their medical record. However, after discussing with the interns, they pointed out a document edited by the gynecological service that detailed a problem that may be related to the current gastric issue.*" **Specialist**

Likewise, when care actors review certain documents, they may deduce the existence of others related to the same care episode. Indeed, treating a particular care episode, for instance, treating a pick in the glycemia, may require different steps that may be documented by various actors in different documents. Therefore, treating this care episode requires various lab tests, a diabetologist's opinion, and a drug prescription. Accordingly, care actors need to read the lab results and the report written by the specialist to understand why a particular drug was chosen over others.

"*When we see a patient suffering from renal failure, we do not document the value of their failure as static data because that type of information may change frequently. Thus, each time we receive a prescription, we search for the exam results describing the evolution of the situation. Because, later, in three months, if the patient comes back with a new prescription and I check what I have, I do not know if, for example, the situation has ever evolved since the last time. When there is a new prescription, we assume that there have been new lab results, and we would need to know and check them to verify that the dosage of the prescribed treatments is correct.*" **pharmacist**

To outline, all the care actors create a record that allows them to maintain their situated overview of the patients' cases to monitor their progress or regression. However, the strategy they employ to use what they gather varies according to the various situations: a routine follow-up or a problem-solving one. Moreover, their interaction with care actors and documents may guide them to browse further documents they did not consider using or adding to their records beforehand.

3.3.3 Challenges Hindering the Practices to Build Overviews of Patients' Cases

Creating an overview of a patient's case is essential to providing continuous and consistent care. However, care actors often encounter several issues that hinder their ability to reassemble medical documents to construct an advantageous overview.

3.3.3.1 Difficulty in Identifying and Contacting Care Actors

One of the primary issues is when care actors need more medical documents depicting a particular part of the patient's case and need to identify the care actors involved in treating those parts. This problem is especially prevalent when patients cannot provide information about their care circle or documents that designate those correspondents. As a result, care actors may have to initiate a blind search to locate the exact person who treated the patient.

"*We must go fishing… I mean, we call the assigned physician [to check if they know who may treat the patient]. If the admission officers inform us the patient has been seeing a cardiologist, but no one knows which cardiologist, we call the cardiologist. If someone in Troyes follows him, we can find out who that is after a few calls, but we do not get any answer if he is followed elsewhere. We try to see if someone in the local hospital is following him. Nevertheless, we do not have access to the email of those specialists {cardiologists working in the local hospital], so we must call in all the services and ask them individually if they have any ideas. It is very, very sorrowful."* **GP_1**

Furthermore, the challenge of identifying the right correspondent is more significant when a patient receives treatment in a health facility. First, a direct line is only sometimes available to contact care actors in different departments. Care actors must contact the facility's switchboard to find the department and correspondents needed. Second, the emergency department or day

hospital teams constantly change according to the shifts. Therefore, even if care actors successfully identify the person who treated the patient upon admission, it may be challenging to reach them. Therefore, as mentioned earlier, care actors often rely on their connections and the people they know within various facilities as the fastest way to identify and reach the correspondents they need.

> "*With the hospital, it is always complicated because you must find the exact prescribing department. The prescription often comes from outpatient consultation, but sometimes from the day hospital. In this case, we call the department written on the prescription. Yet, the person who wrote the prescription is never there. Sometimes, it is not the right service. Sometimes you call, and you will be redirected to the switchboard operators. [...] When the prescription comes from the emergency center, they [the prescription's writers] are mostly just students. Then, we are almost sure they will not be at the hospital the next day after their night shift; In this case, no one wants to take over the responsibility. It is always complicated; we struggle to reach out to people who work in the hospital*." **Pharmacist**

Finding the contact information of care actors with private practices is relatively easy, but contacting them can be difficult due to time constraints. Care actors often refuse to provide their cell phone numbers and ask their assistants to decline calls to avoid spending their working time performing unpaid services. Furthermore, the working hours of care actors with private practices may limit their availability to respond to requests from other care actors.

> "*The problem occurs on Saturdays and especially Saturdays; the problem arises in communication. Generally, we have many hurdles joining doctors during the weekend. All the doctors struggle to join their correspondents on Saturdays. In fact, on Saturday afternoons, very few doctors work. Therefore, when there is an alerting result [Lab results] on Saturday, it is really, really difficult to notify the concerned actors. Therefore, we try to reach either the patients or their nurses. However, when we cannot reach one of them, we call the 15 [The urgent medical aid service] and hand them the information, hoping that they can do something or possibly go and see the patient in the worst case."* **Lab_doctor**

3.3.3.2 Difficulty in Identifying the Right Communication Channel

Care actors must find the appropriate communication channel to send their letters when they want to share summaries with other care actors. However, they often encounter challenges in doing so.

Firstly, the general directory of care actors needs to be updated regularly, which can result in incorrect details about their addresses, emails, or phone numbers. As a result, care actors may hesitate to send summaries to avoid sending them to the wrong addresses.

> "*Updating directories [Care actors' directories] is complicated because, in the directory, you may still find the actors who retired, and even the ones who died are still there. You see, the updates, I do not know how they are done, but it is a real hassle to find anything correct there*" **Endocrinologist_4**

Secondly, care actors use different communication channels to communicate and share with other correspondents. Additionally, in some cases, care actors create accounts in communication tools but use them sparingly. As a result, deciding which channel to use when sending letters can be confusing due to the variety of communication channels available and the potential need for clarity about which channels are actively used.

> "*The difficulty… I mean, the greatest difficulty today is knowing the channels of reception of the person we want to write to. And that I believe we will move one step forward if we use just one simple unified tool. We really wish to write to them [correspondents] without spending time finding a way to do it. The secure messaging system is good, but there are several ones. We do not know which one each person uses, or which is operational. Several doctors called me to say they did not receive my mail. If*

we suggest communicating through a certain channel, I get the answer: "I do not use that tool, or I do not check it at all." In addition, there are secure messaging systems where there is no way to know if the mail has been received and read, a bit like normal mail. This is also difficult. On the other hand, we will know if it is the right address, as we have any refused communication message. But if we do not have a return [about the content of what we shared], we stay on standby." **Endocrinologist_4**

3.3.3.3 Difficulty of Managing Patient Information from Different Communication Channels

Care actors face additional burdens of storing, organizing, and managing patient medical documents received through various channels, especially in paper-based formats. This task becomes more tedious for those working alone without administrative assistance. Thus, they must scan and add the documents to their local EMRs, which can be time-consuming.

"*I cannot work without an assistant. In fact, when we receive the mail, we need to scan them [the received documents] and then integrate them into our system. It is a lot of work if we do not have assistants.*" **GP_4**

Consequently, receiving through the digital tool was considered more convenient as it avoids scanning and allows care actors to download digital documents and integrate them directly into their systems.

"*When they [the other care actors] send a patient, generally it [the document shared] is typed using a word processor. However, to send it, they print it. It would be better if they avoided printing those documents and just sent them to me directly [using digital communication tools] so I could integrate them into my medical record. I will not necessarily need the paper version because afterward, I must scan it to add it to my record; it is a lot of work, a total mess. If there is anything I would like to ask general practitioners and other actors to do, that would be if they want to print their documents out and give them to the patient; they can do it; it is OK with me. Yet, I want them to know that I will not do much with those [the paper version of the document]. I prefer they send them directly [the documents] through any digital communication channel. It is much easier to add to our record, and it will be a huge relief and time saver*" **Endocrinologist_4**

To conclude, creating a record with the different documents depicting the various care episodes and pinpointing the various encounters to treat a particular problem occurring in the patient's care pathway is a central activity allowing maintaining the created overview of the patient's case. However, care actors face challenges in creating and using this medical record due to the diversity of sources and format of documents and the lack of information about correspondents and care actors around the patient.

3.3.4 Conclusion

Through the analysis of the care actors' practices to achieve an overview of the patient's case, our finding revealed that care actors employ individual strategies to create a situated overview focused on their roles, needs, and perspectives to allow them to fulfill their distinct responsibilities while ensuring the coherence of the overall care. However, this analysis allowed identifying similarities between those practices concerning: 1) the way to create a situated overview by gathering, selecting, and organizing documents, 2) the way to enhance the created overview with communication, and 3) the way to use this overview to deliver care. Therefore, we propose a technological solution that supports these practices.

3.4 Discussion and Design Implications

Through analyzing practices that permit achieving an overview of patients' cases within the integrated care context, our results confirmed the challenges identified in the literature that hinder inter-organizational cooperation (Saoutal et al., 2015; Stoll et al., 2010; Svensson, 2019). Indeed, our study confirmed the hardiness of bringing care actors together due to the compartmentalization through the various public and private institutions and the care actors with private practices that do not share the goals or the way of work. Therefore, we could identify the challenges of sharing data about the patient and communicating to ensure the continuity of care.

Similarly, our results confirmed the previous studies in CSCW, highlighting that providing a standardized centralized system that does not comply with the work practices is not the solution to overcome the fragmentation (Greenhalgh et al., 2010; Heeks, 2006; Jagannath et al., 2019; Treurniet & Wolbers, 2021). Indeed, our study revealed that the DMP failed to account for the diverse needs of care actors who partake in patient care (Bertelsen & Bødker, 2001; Jensen & Bossen, 2016). Moreover, the system did not consider their preferred ways of organizing data to optimize usage. Consequently, the system was perceived as an extensive library, leading many care actors to experience confusion as they were unable to retrieve necessary data to facilitate quality care delivery.

Our study highlighted that care actors adopt individualized practices to overcome the fragmentation and gather the medical documents needed to construct a situated overview of the patient's case. Based on the analysis of similarities between those individualized practices, we noticed that they limit their selection and search to the relevant documents responding to their current needs. Thus, when the patient's situation is stable, their situated overview is centered on the documents they produce to document their intervention and track the progress or the regression of the patient. Then, when the situation evolves and requires extra investigation, care actors search for additional elements that enhance their situated overview and expand their understanding of the situation. Previous studies have explored the extent to which clinical overviews are either minimal or comprehensive according to the various situations (Bossen & Jensen, 2014). Yet, our study revealed that the achieved situated overview within the IC context is either minimal, focusing on the local interventions of each care actor, or problem-centered. Therefore, while the comprehensive overview may encompass extensive data about the overall patient's case, care actors focus on selecting the data that allow them to contextualize and solve the problem they are facing. Accordingly, care actors switch from an over-extended overview by browsing anything they receive or get from the patient; to a situated overview encompassing the data they selected to save within the record they create to maintain this overview.

At the same time, previous work highlighted that the degree of comprehensiveness is related to the situation and the problems (Bossen & Jensen, 2014; Levy-Fix, 2020). However, our study highlights that this degree of comprehensiveness is also influenced by the care actors' position and role in the patient trajectory. Accordingly, while the assigned physician requires an extensive overview to coordinate and organize the patient's care, specialists generally focus on a situated overview that guides their treatment. In addition, adherence to medical secrecy limits the overview achieved by paramedics upon potential negotiations to gain access to various medical documents following the gravity of the underlying issue. Moreover, this comprehensiveness is impacted by the possibility of locating and identifying the correspondents owning the medical documents describing the patient's case. The problem accentuates when patients, considered the messengers and the sources of information in IC (Chen & Pine, 2014), cannot provide any information about their care circle leading to a lack of social awareness.

The presented results reconfirmed the role of unstructured data in medical activity (Lovis et al., 2000; Mønsted et al., 2011; Sultanum, Brudno, et al., 2018). Indeed, our study reported the exclusive use of shared medical documents to build an overview of the patient's case. At the same time, we saw that those materials were identified as the initial point of reference for comprehending the many events taking place and understanding the episodes developing in the patient's case. In contrast to prior efforts that focused on creating visualization systems that facilitate gaining an overview of a patient's case by visualizing either the structured data or the content of unstructured data (Kenei et al., 2020; Rind et al., 2013; Sultanum, Singh, et al., 2018) and in providing dashboards to track the chronological evolution of the medical data (Rind et al., 2013), our results contend that visualization displays for IC should: 1) encompass the presentation of shared medical documents as they serve as landmarks, enabling care providers to navigate through the various stages of a patient's case; 2) provide more details than simple metrics to ease the care actors' decision-making process

In practice, care actors reassemble those documents within a record saved in their digital EMRs to maintain their situated overview. However, our results highlighted the struggle of care actors to gather and share those medical documents due to the use of various communication and sharing channels. Indeed, each care actor uses different digital tools to communicate with the other correspondents. Moreover, additional documents are transported by patients or in paper-based format hindering their integration into the digital record. Thus, to address the fragmentation issue and enable care providers to gain an overview of a patient's case, it is crucial to consider the numerous sources that feed the record, maintaining the created overview. These results align with the virtually federated integration approach that permits integrating the various EMRs and offers an additional layer that allows navigating the content of these EMRs (Protti, 2009). Yet, our results suggest that the visualization layer should integrate the various communication channels transporting the medical documents permitting care actors to achieve an overview of the patient's case. We argue that focusing on integrating those different tools will prevent crowding the visualization layers and help care actors organize and focus on the documents they need to fulfill their cooperative work.

In addition, our analysis confirmed that the medical data are context-related and highlighted the need for communication as a component to contextualize and deepen understanding of the developed overview (Bossen & Jensen, 2014). Moreover, this communication is event-driven and centered on shared documents. Similarly, while we confirm the previous results asserting that communication is one way to extend and give details about the data presented within the overview displays (Hertzum & Simonsen, 2015), our results revealed that communication has a pivotal role in guiding the creation of the situated overview. Indeed, the various interactions between care actors may pinpoint and suggest documents that were not considered in the initial overview. Thus, these interactions help care actors find and select more elements to enhance their situated overview. Therefore, while previous studies suggested complementing EHRs with additional standardized communication tools (Richter et al., 2016), we argue that coupling between sharing documents and communication is mandatory to support achieving an overview. Moreover, we argue that coupling between documents and communication will enhance data integration and permits saving the semantic value of the content shared within the documents (Bjørnstad et al., 2017).

Furthermore, alongside the difference between the situated overview perceived by each care actor, the focus on the navigation within this overview changes depending on the situation. Hence, our study confirmed the pertinence of coupling the source, the time, and the problem in the overview visualization (Buchanan, 2017). Indeed, when looking for essential documents to solve problems, care actors start by checking the last edited documents and focusing on the ones

written by specialists. Thus, maintaining an eye on this information while navigating the overview supports temporal and social awareness. Similarly, the use of overview evolves according to the patient's case and the interaction with the various actors and documents. Thus, while overview displays generally focus on displaying the same information to enable shared overview (Jensen & Bossen, 2016), in the IC context, considering the visualization of the various created situated overview is crucial to respond to various needs encountered by the different care actors participating in the patient's care. Moreover, considering the various interactions (Curé et al., 2012) and the visualization trajectories may enhance the care actors' use of the created overview of the patient's case. Therefore, we argue that adopting approaches such as the user interest model (Li & Zhong, 2012) may help the system to learn about the users' preferences and enhance their navigation.

Acknowledging the various practices and challenges faced by care actors to build an overview of the patient's case, we present in the next chapter the implication for the design that supports those practices and encounters the various challenges to identify correspondents, gather documents, and use the created overview.

Chapter 4: Design of CaseOverview

To support an overview of a patient's case and to encounter the challenges we detailed in the previous chapter, we argue that we should design a system that helps care actors collect and review the documents produced around the patient through different settings. The design of such a system aims to provide a tool that helps them coordinate their actions to ensure care continuity and coherence.

Accordingly, in this chapter, we describe CaseOverview, a model of a system we suggest designing to allow care actors to create an overview by collecting and visualizing shared medical documents according to their evolving needs to coordinate the overall medical activities. Therefore, we introduce the design implications to create such a system. Then, we detail some design decisions that translate these design implications into a tangible system. Finally, we use a user-case scenario to describe the various features emanating from the design implications to explain how CaseOverview can ease achieving an overview of a patient's case and support cooperation within the IC context.

4.1 Design Implications Derived from Field Work

In this section, we highlight the various design implications that emanate from our fieldwork results and on which we propose to create a visualization system that fosters achieving overview to support awareness and promote cooperation in the context of integrated care.

Constructing a situated overview of a patient's case is crucial for care actors to gain the necessary awareness to support their cooperative efforts in maintaining a coherent, continuous care service. As outlined in the previous chapter, constructing this overview relies on the shared documents, which act as the overview's building blocks, and the communication, which presents cement that ties the created overview together. As illustrated in section 3.3.2, care actors produce, share, collect and search for documents to create, update and maintain their situated overview of the patient's case, which allows them to proceed with the patient's treatment. Then, using those documents, they construct a medical record, which stores documents about the patient's history from their perspective, allowing them to fulfill their roles.

However, as mentioned in section 3.3.3, care actors struggle to build their situated overview and the medical record that maintains this overview. The lack of familiarity with the actors around the patient, the patient's incapacity to provide information about his care circle, and the existence and use of different communication channels and technologies are the barriers rendering sharing and collecting documents a demanding task. Accordingly, we believe that designing a system that permits care actors to create and customize their situated overview and the medical record needed to deliver care, depending on the documents produced, exchanged, selected, and searched for, will support the construction of the case overview and ease the coordination of the different activities within the IC context.

Moreover, our field study revealed that once actors build their situated overview, they employ different strategies to use it by browsing the documents stored, within their medical records, depending on the various situations and the events arising in the patient's case. Thus, alleviating the system with visualization allows care actors to create situated overviews that respond to their evolving needs, facilitating navigation through the stored documents. We argue that providing situated overviews aligned with care actors' needs will help them focus on the elements they need

to gain insight into the patient's case and prevent them from losing time to look through the comprehensive overview.

Subsequently, we asserted the role of communication and interactions among care actors as essential instruments to validate, consolidate and improve the understanding of the data inscribed within documents, to pass information, and recommend reading. Thus, coupling between the documentation and the communication practices seems vital to cope with their work practices and to offer users the ability to synchronously exchange about the documents they incorporate into their situated overviews.

Accordingly, regarding the previous discussions, we identified twelve design implications intended to create a visualization system that supports the construction of an overview aiming to foster cooperation within the IC context. We will present those implications within two categories; 1) the ones seeking to facilitate the creation of integrated medical records permitting care actors to have a comprehensive overview of the patient's case and; and 2) the ones focusing on easing the customization of the record to allow each care actor to have their situated overviews as well as the ones intended to improve the navigation within the records that maintain those overviews.

4.1.1 Design Implications for Building a Comprehensive Overview

Care actors rely on shared documents to inform and organize the shared actions within the IC programs. Gathering and encompassing those shared documents in one place will provide an integrated medical record that helps care actors construct a comprehensive overview of the patient's case. Therefore, to construct this integrated medical record serving those programs, the system should:

B1: Integrate and Align with the Various Communication Technologies

Systems that aim to support cooperation within inter-organizational cooperation should enable the integration of documents coming from the various communication technologies. Then, once the system integrates and connects with those communication tools, it must provide a visualization layer (see Figure 16) that allows navigation of shared documents.

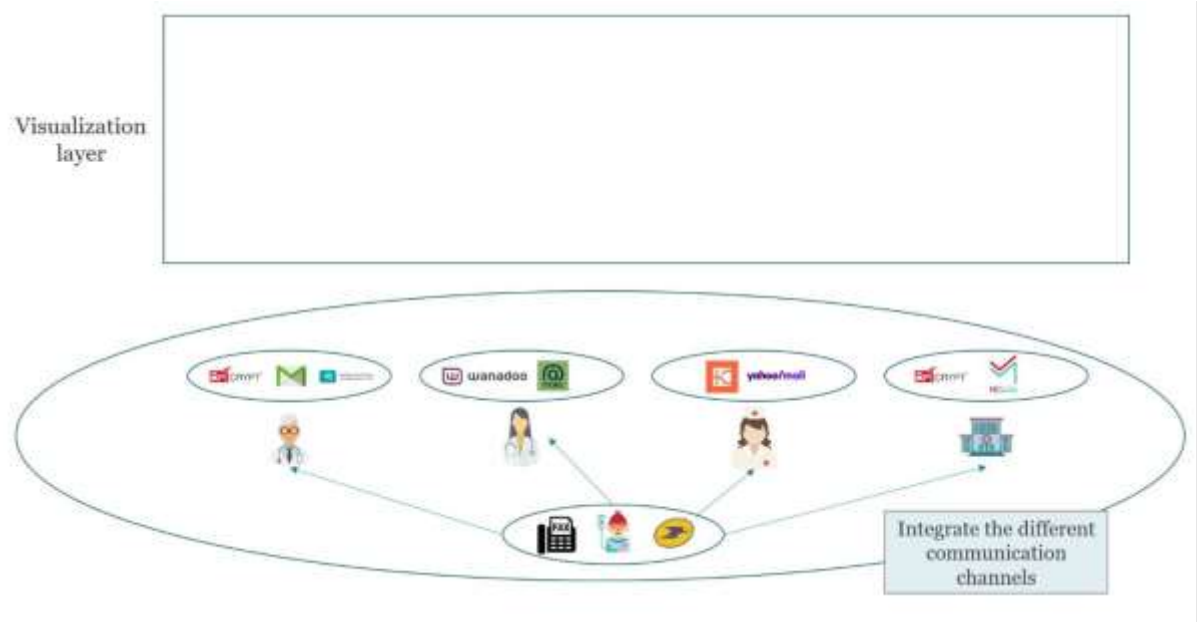


Figure 16 Integrate and align with the various communication technologies

B2: Support an Automated Feeding of the Comprehensive Overview

The system must facilitate the automated collection of shared documents through the different discussions between care actors treating the patient (see Figure 17). Collecting exchanged documents to depict, inform, and highlight new or evolving care events from the different conversations enables care actors to identify emerging episodes where coordination is needed to treat the patient.

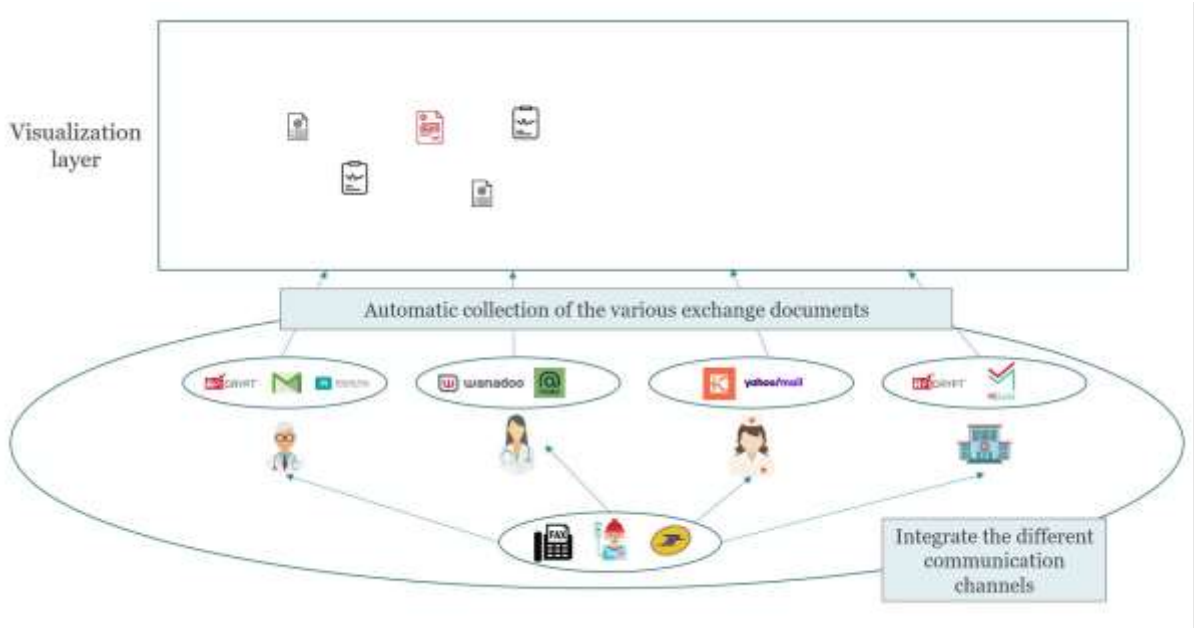


Figure 17 Support an automated feeding of the comprehensive overview

B3: Support a Manual Addition of Documents to Enlarge the Comprehensive Overview

The system should allow care actors to add additional documents, including those sent through traditional communication channels or kept for personal use like summaries, to supplement the comprehensive overview and enable smooth navigation (see Figure 18).

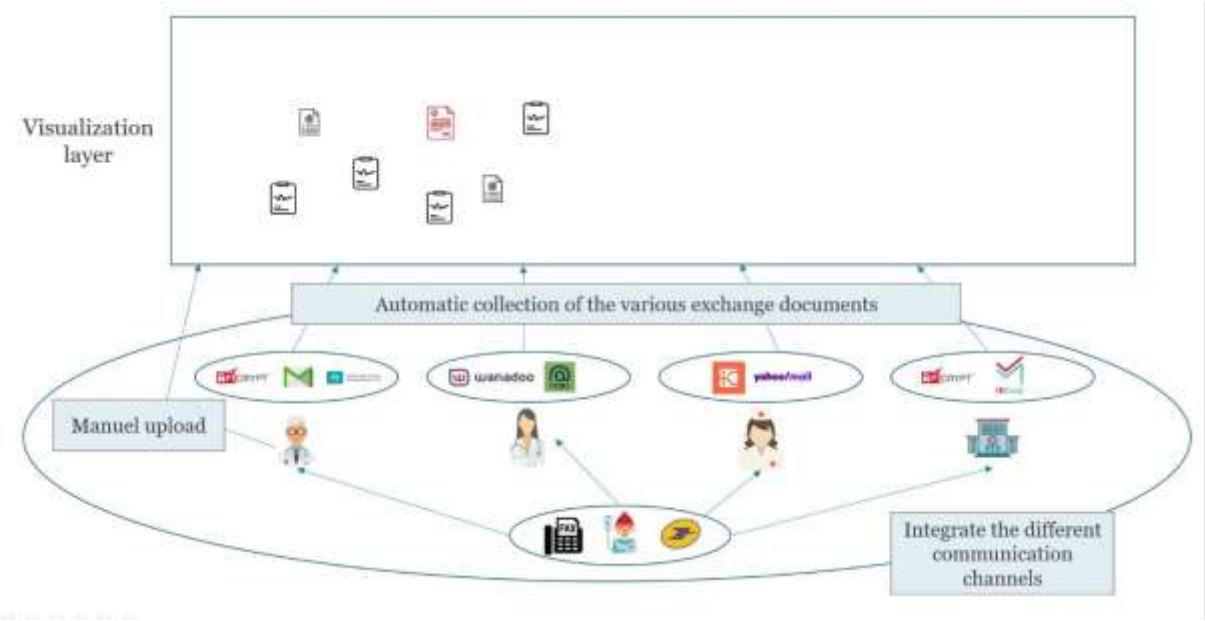


Figure 18 Support a manual addition of documents to enlarge the comprehensive overview

B4: Support Retrieving Documents' Metadata to Ease Information Retrieval and Documents Navigation

After automated collection or upload, the system should extract and save each document's metadata. This information can aid in identifying individuals involved in a patient's care and organizing the comprehensive overview. For instance, acknowledging the care actors who own a particular document will give them full access to their content, while the others will need to submit a request to be able to read the full text. Additionally, metadata about document types and keywords based on content can help prioritize retrieval and guide navigation (see Figure 19).

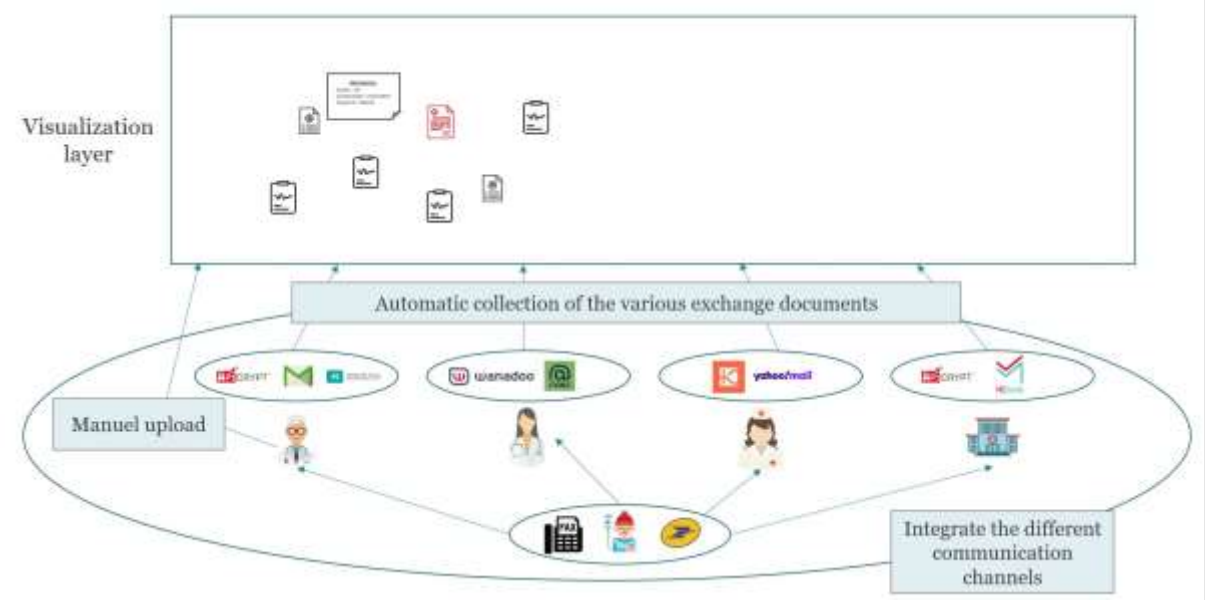


Figure 19 Support retrieving Documents' metadata

4.1.2 Design Implications for Allowing the Creation of a Situated Overviews

Once the system is created, fed with the shared document, and organized based on the metadata extracted from the various documents, the visualization must be configured to shift from the comprehensive overview to offer a situated overview that aligns with the care actors' practices and fulfill their needs.

N1: Tailor the Overview According to Each Actor's Role, Position, and Needs

the system should allow switching from a comprehensive to a situated overview that satisfies their information needs (see Figure 20). The system should provide different levels of information and details based on the user's access permission, displaying documents the user owns first. If additional information is needed, the system should allow the user to search for and include documents from the comprehensive version. For users without systematic access to certain documents, such as paramedics, the system should allow access requests. The system should also offer different granularity levels to visualize documents, details, and full content.

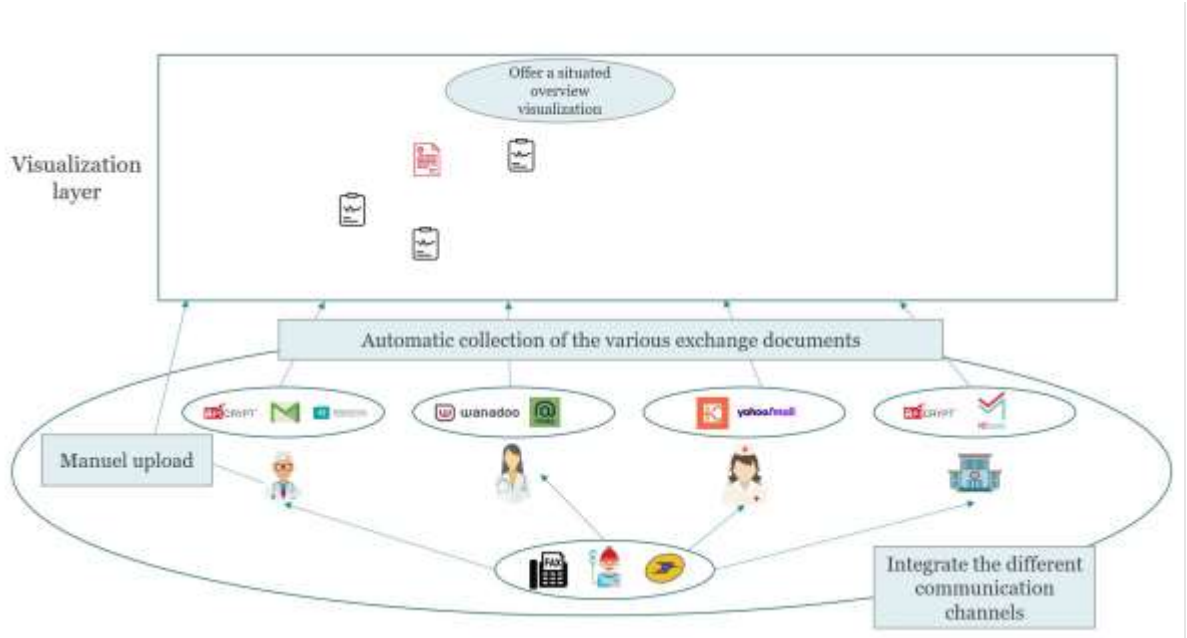


Figure 20 Tailor the overview according to each actor's role, position, and needs

N2: Support Temporal and Social Awareness

Creating an overview of the patient's case requires understanding the care episodes and the stakeholders involved. Care actors collect documents and organize them in an event timeline. To support this temporal and social awareness, the system should emphasize information about document writers and temporality when displaying documents on the visualization. For example, the system could present the visualization in a 2D format that maintains information about origin and temporality (Figure 21).

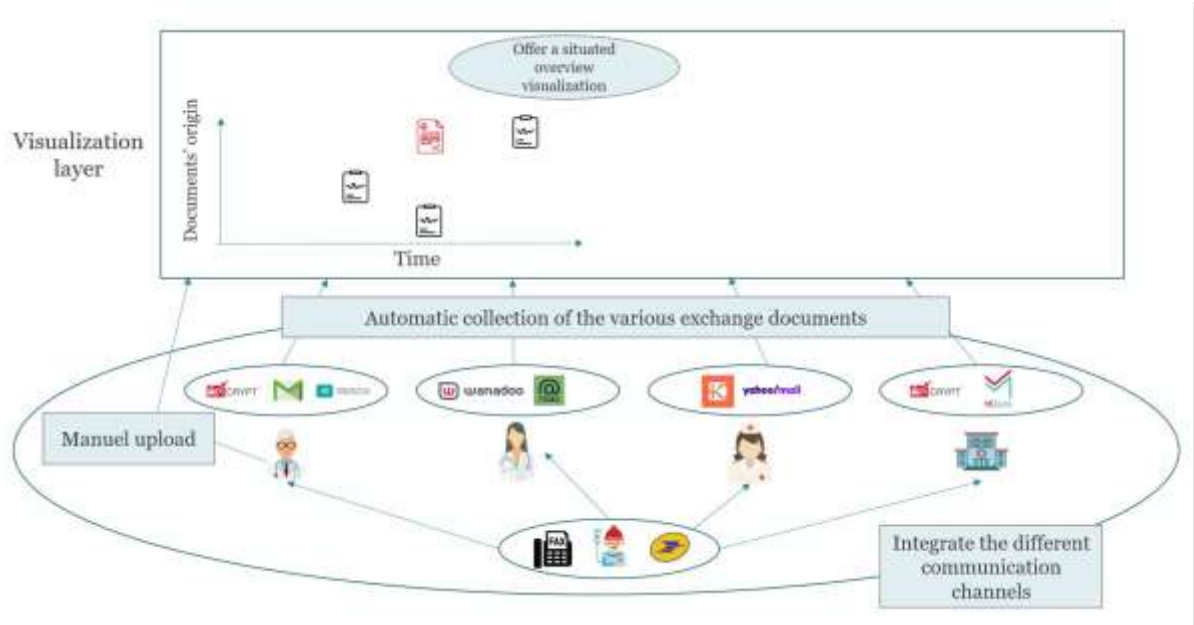


Figure 21 Support temporal and social awareness

N3: Map out the Relationship between Documents

Shared documents may describe different perspectives on the same care episode or be connected in various ways, such as through referral letters and summary responses. The system should enable linking between shared documents to facilitate understanding of their interrelationships. The system should automatically detect connections between request-answer documents, such as prescriptions and laboratory reports. Care actors should also be able to link documents based on semantic connections manually. By visualizing these associations, care actors can browse related documents simultaneously and better understand their contents. This feature mimics how care actors organize documents in their EMR (see Figure 22).

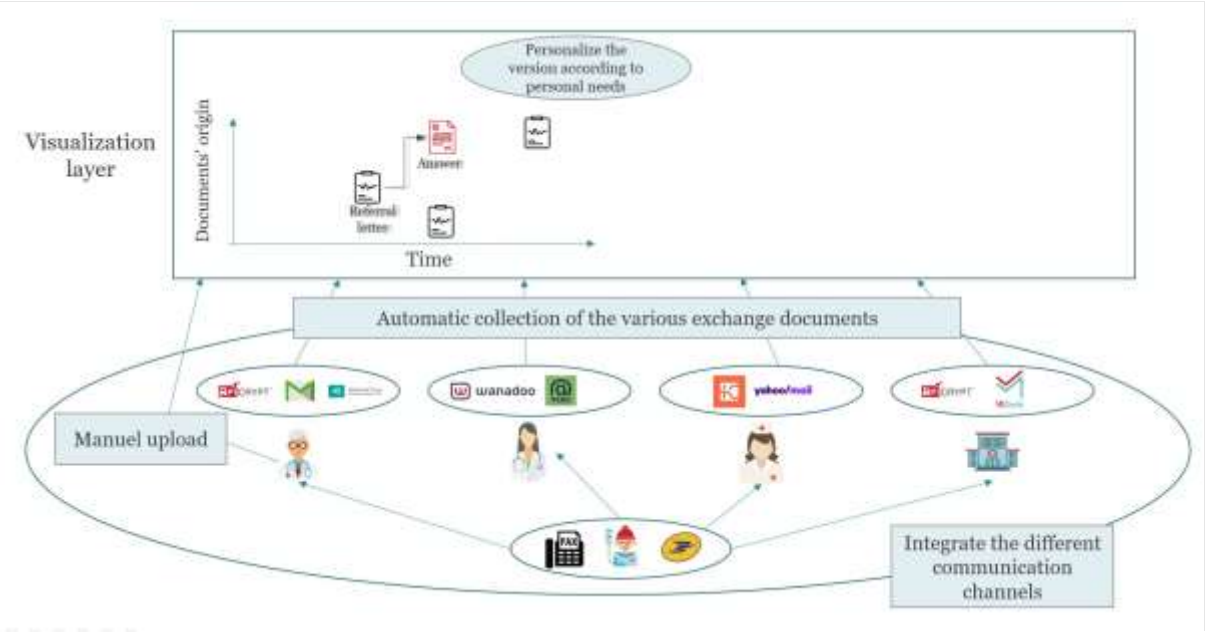


Figure 22 Map out the relationship between documents

N4: Offer Time and Problem-based Navigation Trajectories

Care actors employ different navigation strategies, including time- and problem-based approaches. To support these strategies, the system should offer corresponding navigation trajectories. First, the system should prioritize recent documents for the initial overview or follow-up updates, allowing users to navigate documents chronologically and go backward in time. Second, for more complex situations, a problem-based navigation strategy is necessary. The system should allow users to filter and query the system using text-based searches for problems, procedures, treatments, and other relevant factors to access additional documents that provide insight into the issue (see Figure 23).

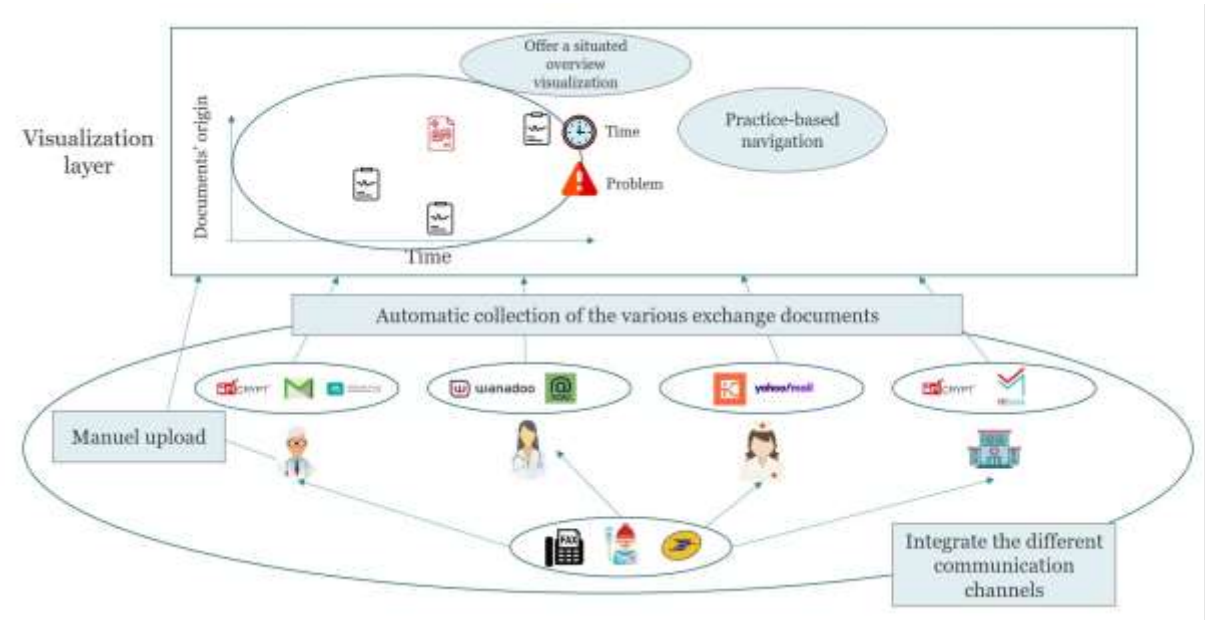


Figure 23 Offer time and problem-based navigation trajectories

N5: Support a Problem-based Classification

The system should allow care actors to classify the documents based on the problems that concern them the most, as the same document can address multiple issues. For example, the system could allow care actors to select a collection of documents and tag them as related to a cluster, which they can access whenever they need to recall information related to the specific problem they are addressing (see Figure 24).

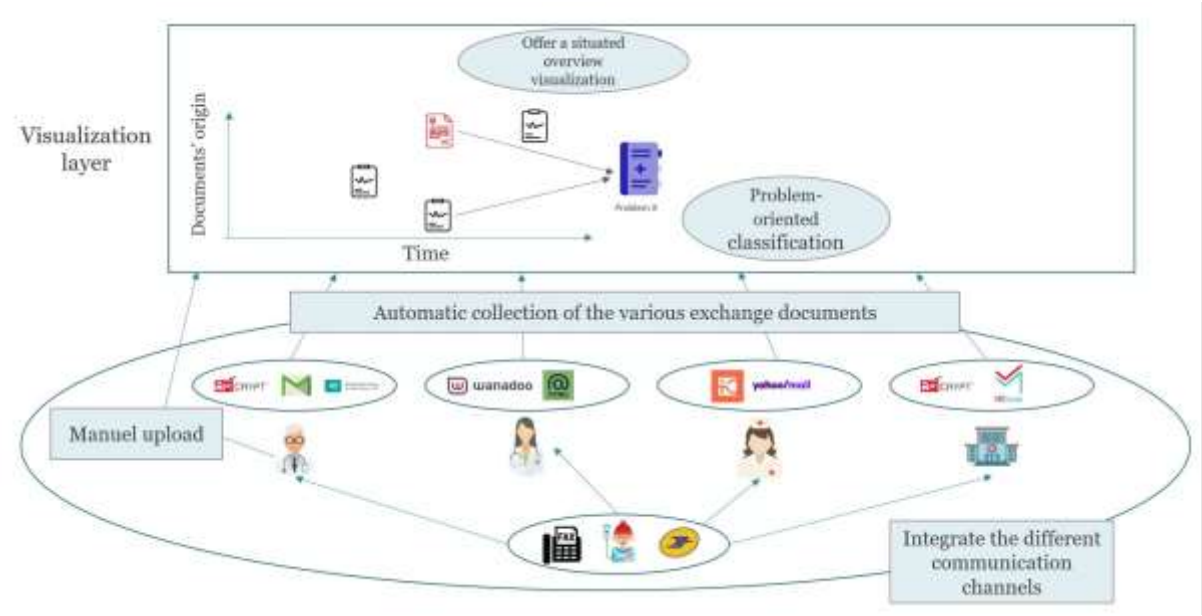


Figure 24 Support a problem-based classification

N6: Support an Interaction-based Navigation

The system should enable interaction-based navigation by allowing care actors to recommend documents and adjust others' situated overviews to highlight suggested elements. It should also suggest related documents based on care actors' interaction with the current document by bringing them to the front of the visualization (see Figure 25).

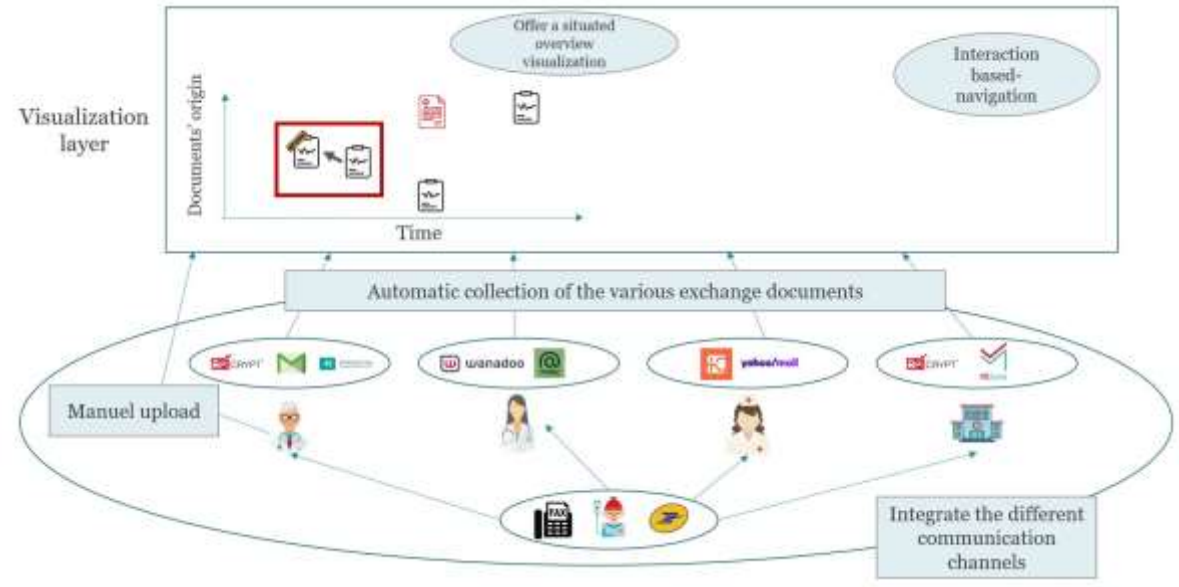


Figure 25 Support an interaction-based navigation

N7: Provide a Local Communication Space

The system should have a built-in communication feature that allows care actors to directly communicate and contextualize the information they review within the shared documents. This communication space should also allow them to provide further details about the patient and alert each other during emergencies. Moreover, the system should enable care actors to save the pertinent messages as comments attached to the concerned documents, making it easier to understand their content and discuss the patient case generally.

N8: Create a User Profile to Enhance Future Navigation

The system should create a user profile that stores information about each care actor's navigation trajectories and suggests browsing documents similar to those they generally review. It should also learn about the personal problem-based clusters created by the user to suggest adding recently added documents that treat the same issue they are following. Furthermore, once the profile is created, the system should be able to recommend similar visualization configurations to other care actors with similar roles or professions.

4.2 Technological Opportunities and Limitations

Developing a system that follows our design guidelines needs to consider the different technological solutions that allow for the extraction of documents and their content, the classification of those documents based on their type, and the storage of the extracted documents for navigation in a visualization layer. This section outlines the various technological solutions and their current limitations.

1. **Integration with digital communication tools:** The system should consider and integrate the various communication tools used to exchange medical documents. A viable approach entails the development of an add-in extension, which care actors can install within their professional communication tools. Therefore, while users peruse their email correspondence, the add-in actively identifies and extracts documents and their associated metadata, such as patient information. Subsequently, it proposes to the user the option to upload the received document to the visualization layer. Simultaneously, the add-in offers the capability to enable the automatic upload of subsequent documents received in the future that are linked to the same patient. Yet, this approach faces different challenges:
    a. The add-in has to use the APIs proposed in those various communication channels to ensure the connection between the add-in and the communication tools. Yet, we may face issues related to the APIs' availability and the integration complexity, as each channel may have its own API structure, authentication mechanisms, and data formats.
    b. The add-in may face compatibility issues with different operating systems, devices, or versions of communication platforms. It may require additional development efforts to ensure smooth functioning across various environments.
2. **Storage:** The system needs a way to sustainably store documents that are part of the created overviews. Mail servers holding the documents may have different policies determining how long the documents are stored. Thus, the system needs to provide a way to care actors to store the exchanged documents. Looking at the current state of technology, we see two possible options:

- The first option is to allow care actors to upload the documents they receive to their local storage, which ensures that the documents are available even if the mail server is not working. The system can then share information pointing to these local documents with other care actors. Care actors can send requests to access the needed documents in this scenario. However, relying solely on local storage does not guarantee that the medical documents will be kept safe in case of problems with the local storage.
- The second option is to allow the system to automatically upload the received documents to a centralized storage location. Care actors can then decide whether to make everything uploaded from their mail server publicly accessible or decide separately for each document. The system should also allow users to review a log file showing who has accessed their documents. However, creating a centralized database presents challenges as it requires complying with government guidelines for hosting medical information.

3. **Documents extraction:** Care actors rely heavily on digital communication tools for sharing medical documents. To effectively manage these documents, the system needs to extract them from the various messaging services to feed the visualization layer. To achieve this, system developers must accommodate each messaging service's protocols. In addition, access to these documents depends on the privacy policies of the messaging service, the terms of use set by the supplier, and the protocol used by the mail server. Therefore, these factors must be considered carefully to ensure documents' secure and compliant extraction.
4. **Metadata extraction:** To display a document in the visualization layer, the system must associate it with a specific patient and possess pertinent information regarding its author, date, and owners. To ensure the unique identification of each document and secure message exchange, the French government encourages using the INS number[32], which identifies the patient to manage the patient's medical data. Consequently, to collect metadata, developers must extract email headers that indicate the author, receiver, date, subject, and INS number. This can be accomplished by employing a programming language and utilizing the APIs provided by the mailing server. The extracted data must then be parsed and stored in a centralized database to facilitate visualization. However, access to the email message sources and APIs necessary for extracting email headers depends on the service provider and their respective security policies.
5. **Content extraction:** extracting the content from the documents is essential as it enhances the metadata content that describes the documents and facilitates the navigation and retrieval of the searched document. Thus, we can use NLP and semantic analysis tools to get the core themes, keywords, concepts, and relationships between those extracted data (Gopan et al., 2020). Moreover, the system should be able to construct a dictionary to map the relationship between the extracted terms and point out the synonyms to refine the results of document retrieval. However, the extraction's success and accuracy depend on different points. First, medical documents can be scanned and have an image-based format. Therefore, they require additional work to convert the image to text using other techniques, such as optical character recognition (OCR) (Singh, 2013). Second, the accuracy of the extracted data can also be altered

[32] The Identité Nationale de Santé (INS) is a unique identification system for patients in the French healthcare system. It is a national identification number that is assigned to each person receiving healthcare in France.The INS was created in 2016 as part of the law for modernizing the French healthcare system. Its goal is to facilitate the management of patient health data, by enabling better coordination between different healthcare providers and improving the quality and safety of care.

depending on the quality of the text, for instance, the spelling errors, the use of acronyms, and the grammar mistakes. Therefore, the system should ask care actors to validate the extracted information upon uploading.

6. **Document classification:** Identifying the various types of documents may enhance and ease the navigation through the personalized version of the medical record. Therefore, the system should classify the extracted documents, based on their contents, into the general type of medical documents, for instance, prescriptions, lab results, letters, and images. This can be achieved by considering the documents' structure and using text-mining techniques, such as TF-IDF (Bafna et al., 2016). However, these techniques may encounter accuracy issues depending on the volume and the dataset's quality. Therefore, we argue that the system should require validation from the care actors adding the documents.

4.3 Translation into CaseOverview System

This section presents our attempt to translate the previously defined design implications into a system called CaseOverview. Adopting a scenario-based design approach (Rosson & Carroll, 2009), we present below use-case scenarios that illustrate how users can integrate CaseOverview in their practices.

Inspired by the data collected during our fieldwork, the scenarios intend to present a case of a persona, Mrs. Dupont, a 45-year-old woman with a history highlighting surgical episodes, diabetes, and weight imbalance. Recently she moved back to her hometown to be close to her mother, who has Alzheimer. Moreover, the scenario includes four other different personas, featuring the care actors treating the patient and using the tool to create an overview of her case: 1) Dr. Traitant, a general practitioner whom Mrs. Dupont started seeing following her relocation and who she nominated as an assigned physician; 2) Mrs. Dieteticienne, a dietician that manages the diet plan; 3) Dr. Pharmacien, a pharmacist who deliver the drugs prescribed for Mrs. Dupont, and 4) Dr. Oncologue, a specialist oncologist that Mrs. Dupont sees to treat an oncological problem.

Therefore, in the following subsections, we walk through the different steps in the different scenarios presenting how the personas use CaseOverview to create and update an overview of Mrs. Dupont's case, get and solve information during emergencies, and work together to treat Mrs. Dupont. Within the different steps, we explain the functionalities derived from the design implications we pointed out by their enumeration. At the same time, we will present Mock-ups that illustrate the described steps and functionalities[33].

4.3.1 Creating and Updating an Overview of a Patient's Case

Dr. Traitant met Mrs. Dupont after her relocation to follow her diabetic treatment. Thus, since it was their first meeting, he wanted to know her past and understand the various care episodes she went through to decide what he would do next to follow up. Thankfully, the previous documents detailing Mrs. Dupont's case were exchanged through digital communication tools. Therefore, When Dr. Traitant installed the CaseOverview add-in with the communication tools he uses, for instance, ApiCrypt, MSsanté, and Gmail, then he accessed CaseOverview's visualization and added Mrs. Dupont, he could find her created medical record (see Figure 26) **(B1) (B2) (B3)**. Dr. Traitant wanted insight into the care problem she has been treating, her antecedents, and

[33] https://www.figma.com/proto/s8oZk4cVSFNzk9pGY5NKDs/CareKnot-Project?type=design&node-id=707-18&scaling=min-zoom&page-id=152%3A2&starting-point-node-id=707%3A18&show-proto-sidebar=1

current treatments. Therefore, he reviewed the top panel (the zone in blue), where he spotted the general information about Mrs. Dupont, including her full name, her National Health ID (INS), some of her antecedents and problems, and her current treatments. At the same time, he wanted to know the actors around Mrs. Dupont who participated in the treatment of the issues he identified in the top panel. Thus, he checked the right panel pinpointing the care circle list that showcases care actors who had previously seen, treated, and exchanged around Mrs. Dupont **(N2)**. Afterward, Dr. Traitant desired to check the documents exchanged to depict the different care episodes. Therefore, he focused on the large portion of the screen displaying his situated overview, allowing him to review and browse the documents he shared, received, or included during the previous browsing. However, since it was the first time Dr. Traitant saw and accessed Mrs. Dupont's record, his situated overview was empty (see Figure 26) **(N1)**. Therefore, the system suggested switching to the 360° view, presenting the comprehensive overview, which encompasses all the documents produced and exchanged around Mrs. Dupont **(B2) (B3)**. The content displayed within the 360° views can be spotted and visualized by all the care actors using CaseOverview. Then, according to each care actor's needs and interactions with the content, their situated overview can be customized to include only the elements they need.

Once Dr. Traitant switched to the 360° view, he could visualize the different exchanges around Mrs. Dupont during the current year (see Figure 27). The different documents were displayed in a 2D canvas where the x-axis of the canvas showed time, and the y-axis highlighted the specialties of the various documents' authors **(N2).** Moreover, within this representation, the documents are presented using dots with different colors that refer to their types. At the same time, the various documents exchanged within each month are regrouped within clouds that Dr. Traitant hovered over one by one to visualize the word clouds that describe each documents' cloud. For instance, Dr. Traitant saw that Mrs. Dupont had been taking the same drug for several years and was seeing a dietician, Mrs. Dieteticienne, once each quarter of the year to check on her dietetic care plan **(N1)**.

Afterward, Dr. Traitant wanted to focus on last month's care episodes, so he clicked on the last documents' cloud. Thus, the visualization changes to concentrate on the chosen period. The x-axis displays the selected month, while the y-axis displays the specialties engaged in the displayed documents **(N2)**. Documents, presented with different icons to help the care actors differentiate their types, were dispersed on the canvas and centered at the intersection between their creation dates and the specialties that generated them **(N2)** (see Figure 28).

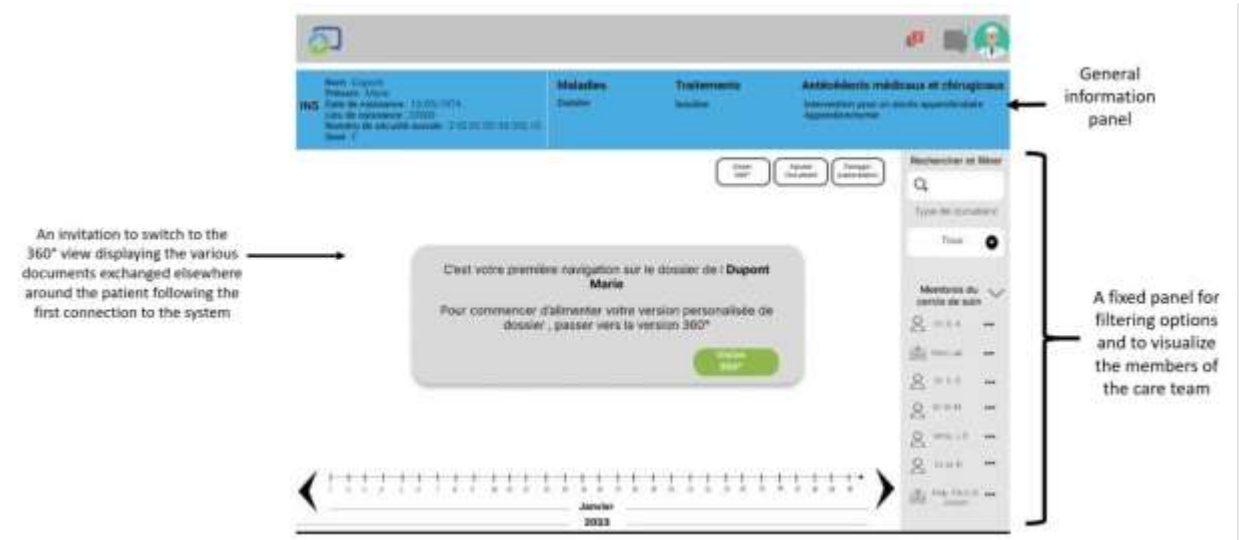


Figure 26 The first visualization displayed following the first access to a medical record

Dr. Traitant decided to check the last lab results. Therefore, he clicked on the icon presenting the document received from the medical laboratory. Then, he reviewed a panel that appeared on the left to check the keywords describing the documents and the care actors that had already received the document. Then, he clicked the "visualize" button to open the full text (see Figure 29). By reviewing the lab results, this document is automatically added to Dr. Traitant's situated overview **(N1)**.

Next, Dr. Traitant saw links that associate documents that refer to a specific connection between them **(N3).** For instance, he identified a document that presents a post-operative report, which is linked to a referral letter and another post-operative report. Accordingly, Dr. Traitant reviews their details to get their context and analyze the relationship between the interventions made by the document's authors **(N3)**. Therefore, he understood that Mrs. Dupont had appendicular abscess surgery following abdominal pain and was referred to the day hospital, where she had an appendectomy. Then, he manually added those documents to his situated overview. Therefore, he selected those documents and clicked on the "include document" button, and consequently, his situated overview was updated with the documents included **(N1)**.

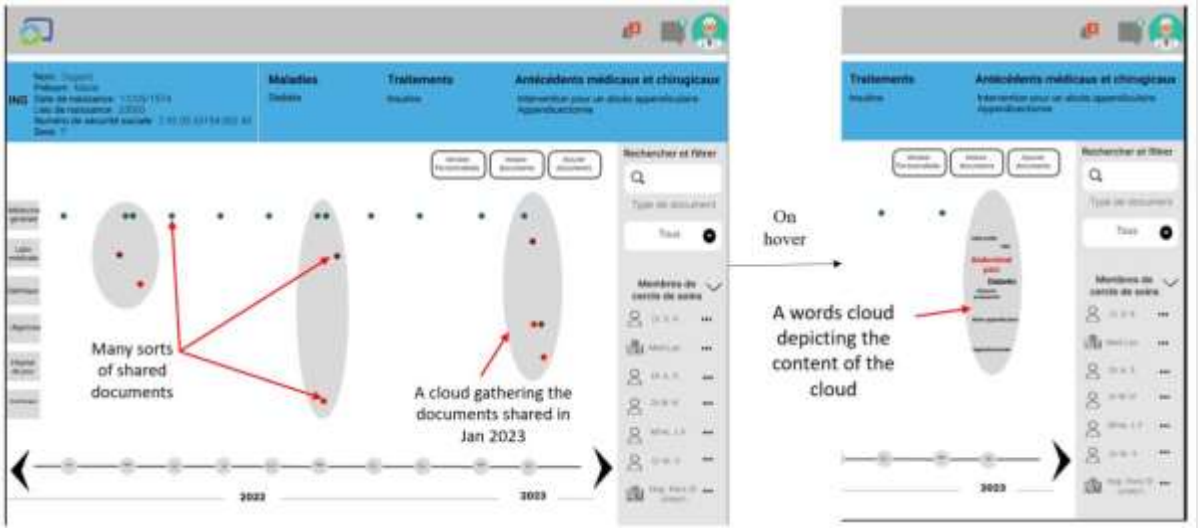


Figure 27 An extended comprehensive overview visualization

Dr. Traitant created an overview of Mrs. Dupont's case by following and browsing the current and previous care episodes. Then, during the encounter with Mrs. Dupont, who described recurrent abdominal pain, he prescribed blood tests and pelvic ultrasound and fixed a follow-up appointment in two weeks.

Mrs. Dupont returns for her appointment in two weeks with her documents printed. During the encounter, Dr. Traitant reviewed CaseOverview, where he could find the lab results and the pelvic ultrasound report, which he included in CaseOverview visualization using the CaseOverview's add-in when he received the documents through his MSsanté account. Those documents appeared in the visualization linked to his prescriptions (see Figure 30) **(B1) (B2) (N3) (N4)**. Following their review, Dr. Traitant noticed a disturbance in her blood test results. Therefore, he decided to request a report from her dietician, Mrs. Dieteticienne, to have more insight into her current dietetic plan and how it can be enhanced to adapt to her current situation.

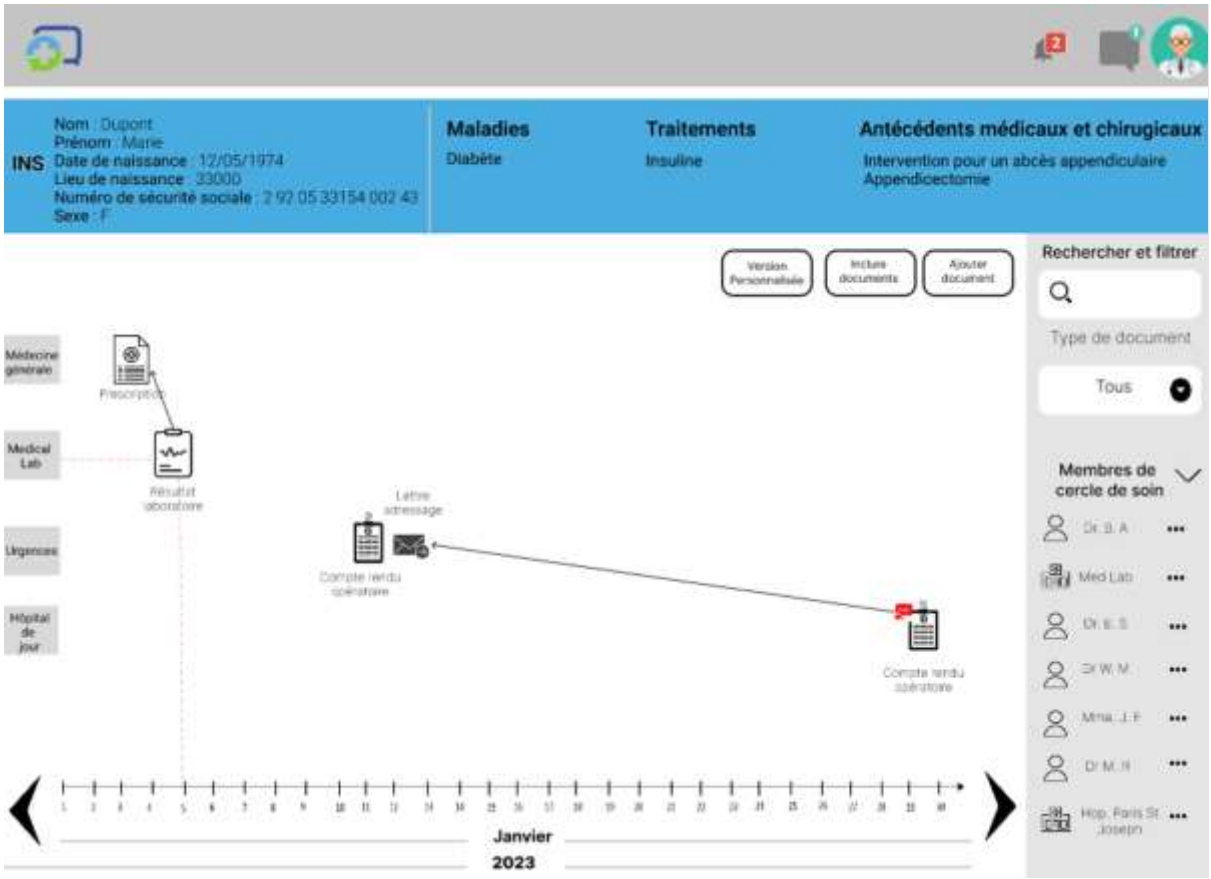


Figure 28 A detailed, comprehensive overview visualization

Upon receiving a request letter in her ApiCrypt account, Mrs. Dieteticienne was presented with the opportunity to incorporate it into her situated overview on CaseOverview through the add-in **(B1) (B2)**. This seamless integration was facilitated by the add-in's ability to detect the identity of Mrs. Dupont in the received document and subsequently suggested its inclusion within her comprehensive overview. Therefore, once she opened CaseOverview, she saw the letter, edited by Dr. Traitant, in front of her situated overview visualization **(N1) (N4).** Therefore, to answer Dr. Traitant's request, she wrote a summary highlighting the things that have been done with Mrs. Dupont recently that she sent back through ApiCrypt. Following the receipt of the mail, Dr. Traitant was able to conveniently review the document associated with his request directly within his visualization interface **(N3) (N4)**. This was facilitated by his prior selection of the option allowing the add-in to automatically upload all documents pertaining to Mrs. Dupont **(B2)**. Afterward, he prescribed a new treatment and fixed a follow-up appointment in one month**.**

4.3.2 Digging in to Update the Overview and Solve Problems

Two weeks before the fixed appointment, Mrs. Dupont requested an urgent appointment to see Dr. Traitant. During the encounter, Dr. Traitant noticed a considerable weight loss, and Mrs. Dupont explained that she suffered from a similar weight loss as a teenager. Thereupon, Dr. Traitant decided to check the documents related to this problem. Therefore, he opened CaseOverview and typed a query in the filtering area to look for anything related to weight loss **(N4).** Then, the visualization sends the current documents to the background of the visualization and brings the documents that answer the query to the front **(N4)** (see Figure 31). Dr. Traitant browsed the documents highlighted in red and then created a cluster to save the documents he reviewed. The created cluster appeared in the left panel under the care actors' list **(N5)**. By saving

the search results within the cluster, Dr. Traitant can keep up with the evolving treatment of weight loss recurrent problems. Then, to proceed with the treatment of Mrs. Dupont, Dr. Traitant decides to prescribe extra tests and a pelvic CT scan.

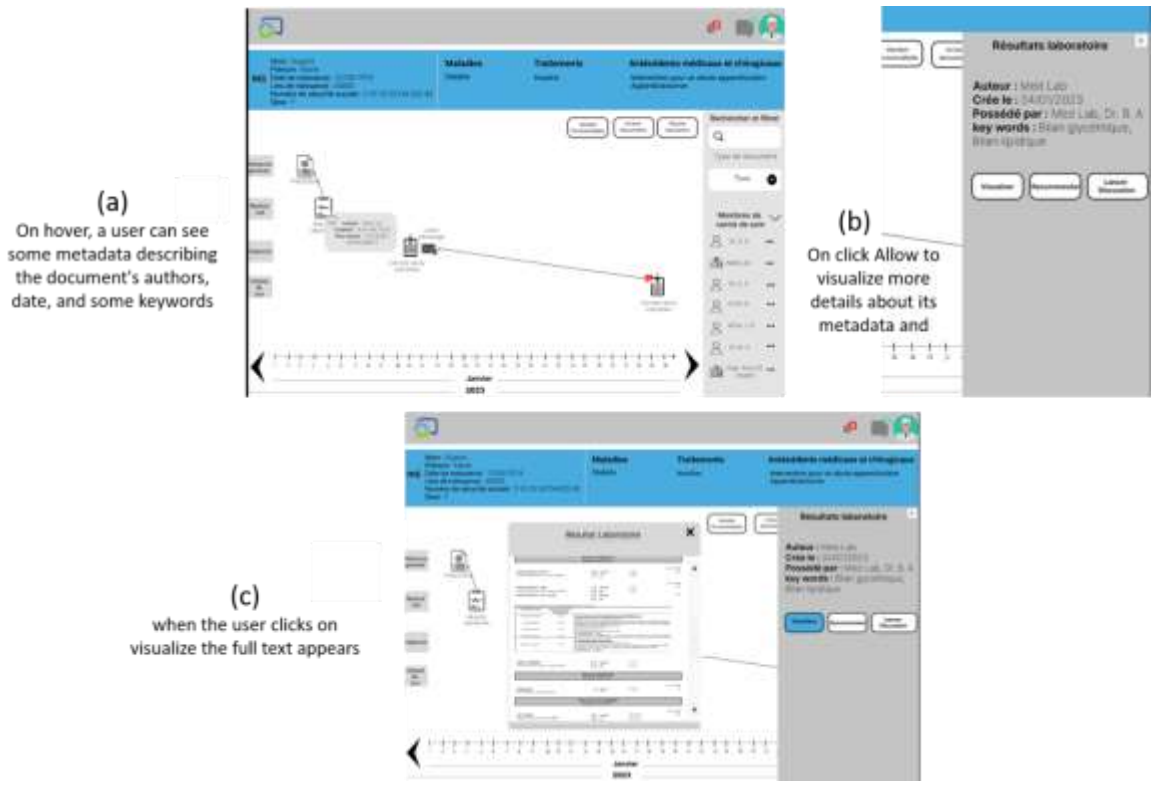


Figure 29 The three levels to visualize a document

Two days later, Dr. Traitant received a report from Mrs. Dupont's previous assigned physician, which was forwarded through the postal mail. Once the new report was manually added to CaseOverview **(B3)**, Dr. Traitant saw that it was generated a month after the second surgery and edited by the Department of Pathological Anatomy and Cytology **(N2)**. Then, by visualizing more details about it, he discovered that it was a pathological examination result explaining the existence of a tumor. Thus, he linked this document with his recent summaries and the post-operatives' reports **(N3)**, saved those documents in a new cluster **(N5)** (see Figure 32), and edited an urgent referral letter to send Mrs. Dupont to see an oncologist Dr. Oncologue.

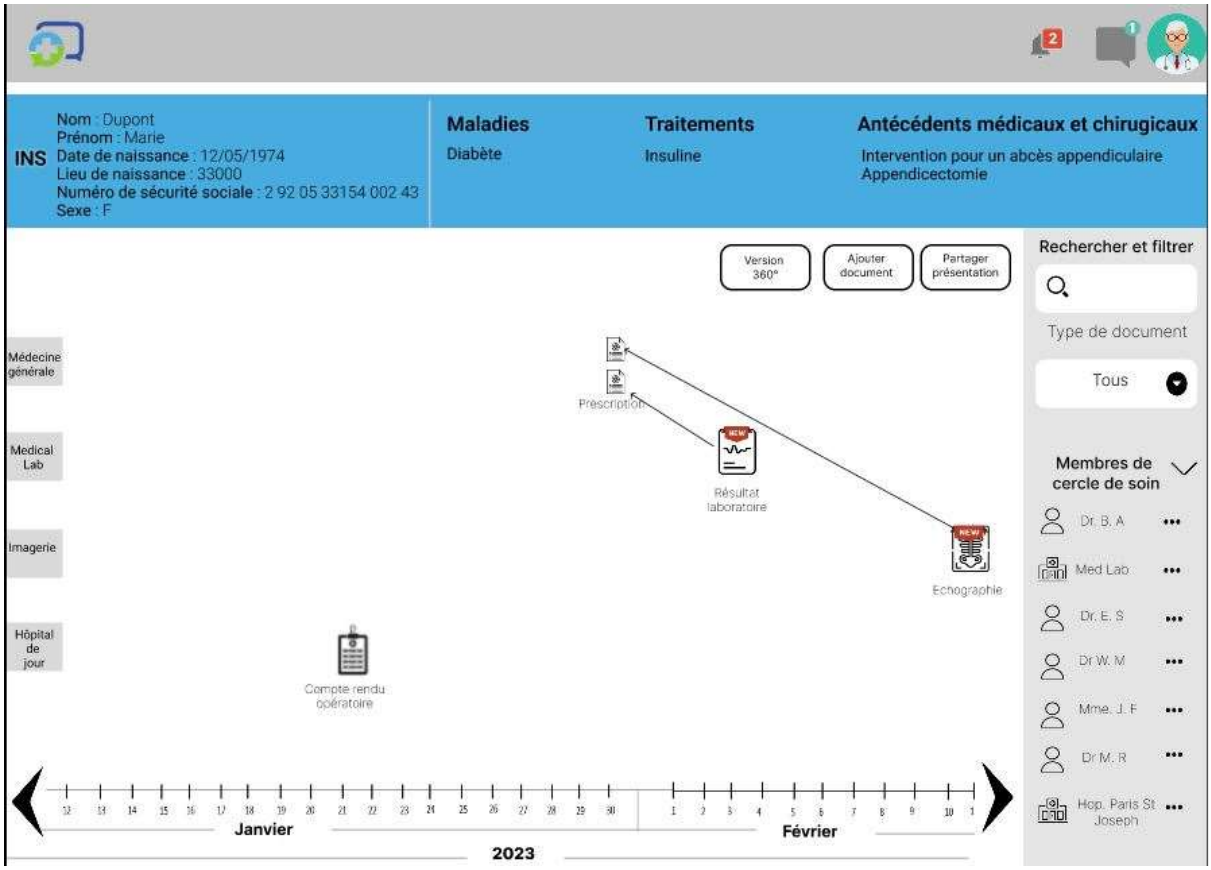


Figure 30 The visualization of the recently added documents

4.3.3 Working Together

As we mentioned, CaseOverview is an integrated medical record encompassing the parts of the medical record that help care actors working within IC create, update and maintain a comprehensive overview of the patients' cases. At the same time, constructing this overview, in many cases, requires collective work where different actor exchange to confirm and enhance their collective understanding. Therefore, CaseOverview intends to offer functionalities that allow them to contribute to each other's situated overview.

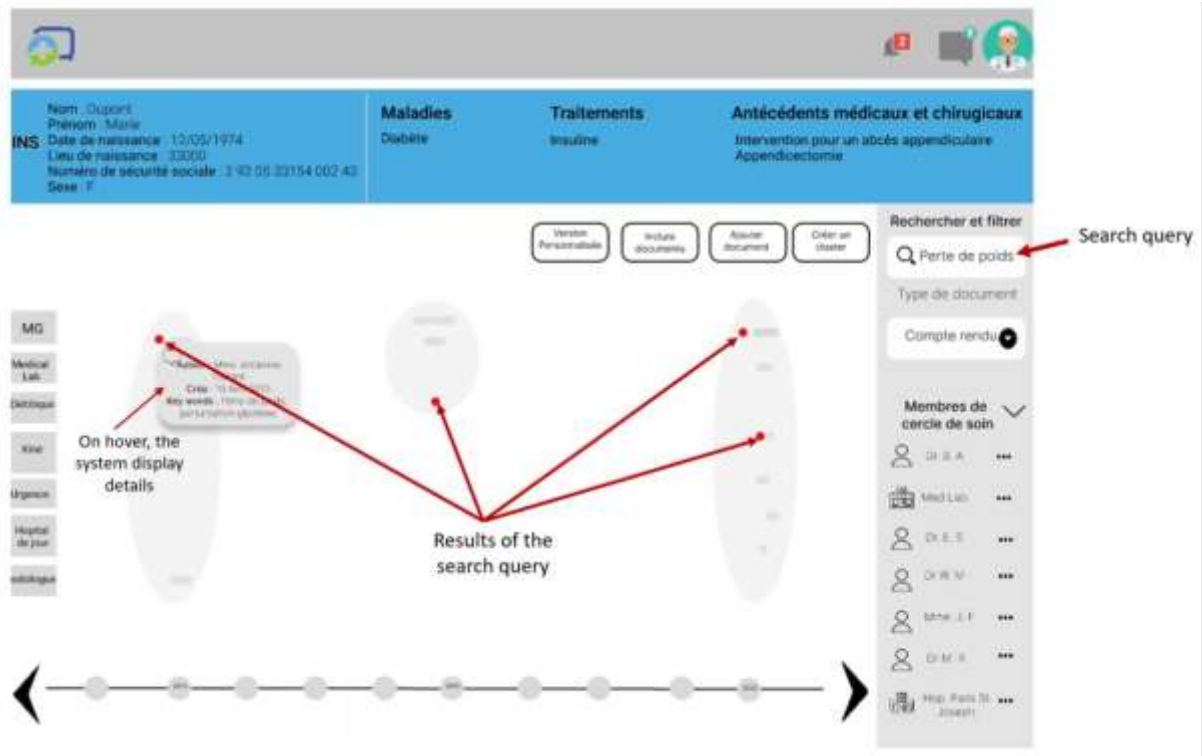
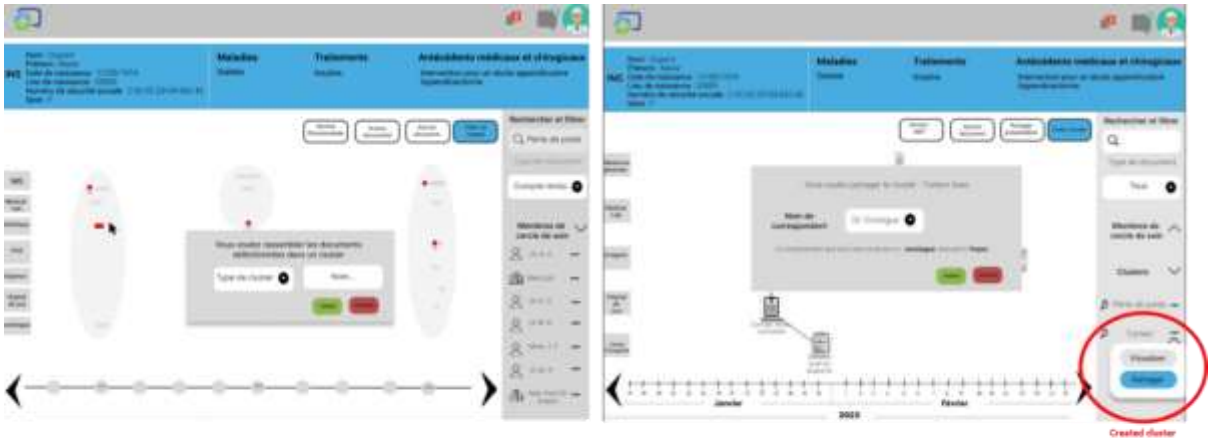


Figure 31 Visualization of documents that answer a search query

For instance, following Mrs. Dupont's appointment with Dr. Traitant, where he prescribed a new treatment, she went to the pharmacy to buy the new drug. Dr. Pharmacien, the pharmacist, uploaded the prescription in CaseOverview **(B3)**. Then, when he checked the history of the drugs he had been delivering, he noticed that the prescribed medication had changed. Therefore, he opened Mrs. Dupont's profile and reviewed the recent documents in the 360° view. Dr. Pharmacien spotted recent lab results just before the delivery of the new prescription. Therefore, he decided to exchange with Dr. Traitant to obtain information pertaining to the laboratory results that he posited served as the impetus for the transition to the new medication. Thus, Dr. Pharmacien clicked on the prescription icon and started a discussion with the document's author **(N7).** A tab appeared to allow the care actors to exchange. Therefore, Dr. Pharmacien sent a message asking about the reason behind the shift to the new drug and explained that he desired to verify the correct dosage. A few moments after, Dr. Traitant responded, explaining the distribution of the blood sugar levels **(N7)**. Accordingly, Dr. Pharmacien had an insight into the current situation and the reasons motivating the need to switch to a more potent drug.

Then, Dr. Pharmacien decided to tag this information as a comment on the prescription. Therefore, the other actors who may consult the document later will understand the reasons behind the switch to the new medicine. Thus, when they click on the document, and the left panel showing details about it appears, they can find any comment tagged with the document to clarify its content **(N7)**. At the same time, Dr. Traitant wanted to update the general information section. Therefore, he decided to tag the message he exchanged with Dr. Pharmacien about the prescription that mentions the new drug's name. Consequently, he clicked on the information icon on the left of his message and chose the general information tag.



(a)
Grouping the result of the reviewed document within a fixed cluster to have them available for future use.

(b)
Sharing the created cluster with other care actors interested in the same care episode

Figure 32 Creating and sharing clusters

A pop-up asks Dr. Traitant to choose from a list the type of information he is adding: a health problem, a current treatment, or a social situation. Once he clicks on a current treatment, the pop-up asks him if it is a new treatment or a substitution for an old one. He clicks on the second choice to clarify that Mrs. Dupont switched to a new drug, and the top panel of Mrs. Dupont's record is updated with the new information (see Figure 33).

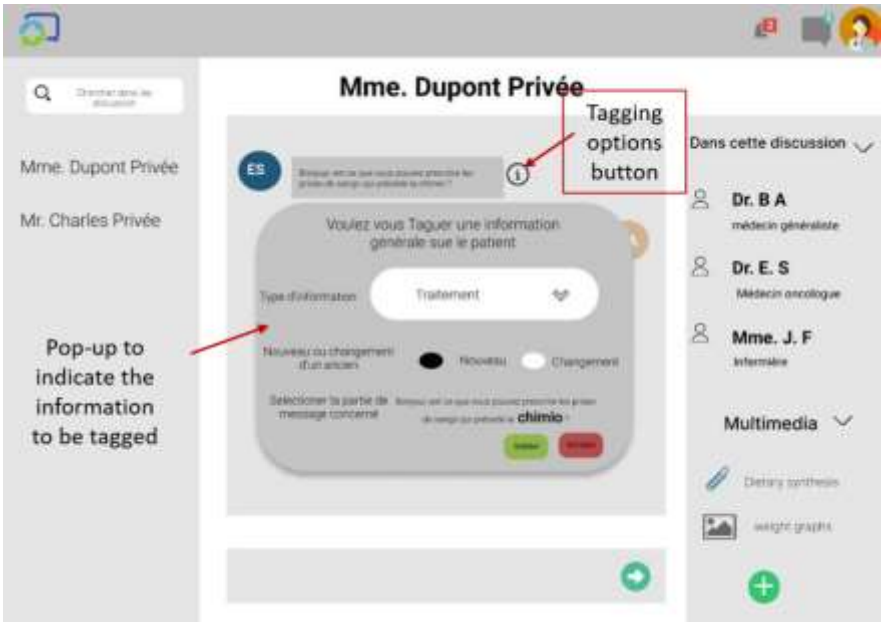


Figure 33 A discussion about a patient

Alongside the functionalities allowing the discussion to consolidate the understanding and cooperate to build a comprehensive overview of the patient's case, CaseOverview offers functionalities to allow actors to suggest navigation trajectories that fasten the creation of a situated overview.

For instance, when Dr. Traitant referred Mrs. Dupont to an oncologist, she quickly fixed an appointment with Dr. Oncologue. During the encounter, Dr. Oncologue opened CaseOverview to check Mrs. Dupont's profile and found out that Dr. Traitant recommended configuring the

situated overview of Dr. Oncologue to show the cluster he created rather than the last edited documents **(N6)** (see Figure 34). Therefore, Dr. Oncologue reviewed the referral letter sent by Dr. Traitant, the post-operative reports, and the pathological examination result **(N6)**.

Moreover, as Dr. Oncologue generally focuses on checking scans and lab results for his other patients, CaseOverview considered the history of his previous interaction and recommended visualizing the recent lab results and the pelvic ultrasound and CT scan **(N6) (N8)**. At the end of their encounter, Dr. Oncologue prescribed home chemotherapy sessions. Following the reception of the Document, Dr. Traitant and Dr. Oncologue started a discussion to exchange about the organization of the treatment, the role of the specialist and the assigned physician in ensuring the follow-up sessions and the need to prescribe a periodical Cell blood count (CBC) test that a nurse must perform before each session. During this exchange, the two actors tagged the information about the new treatment, the home hospitalization organization, and the social situation indicating that Mrs. Dupont will be on partial sick leave **(N7)**.

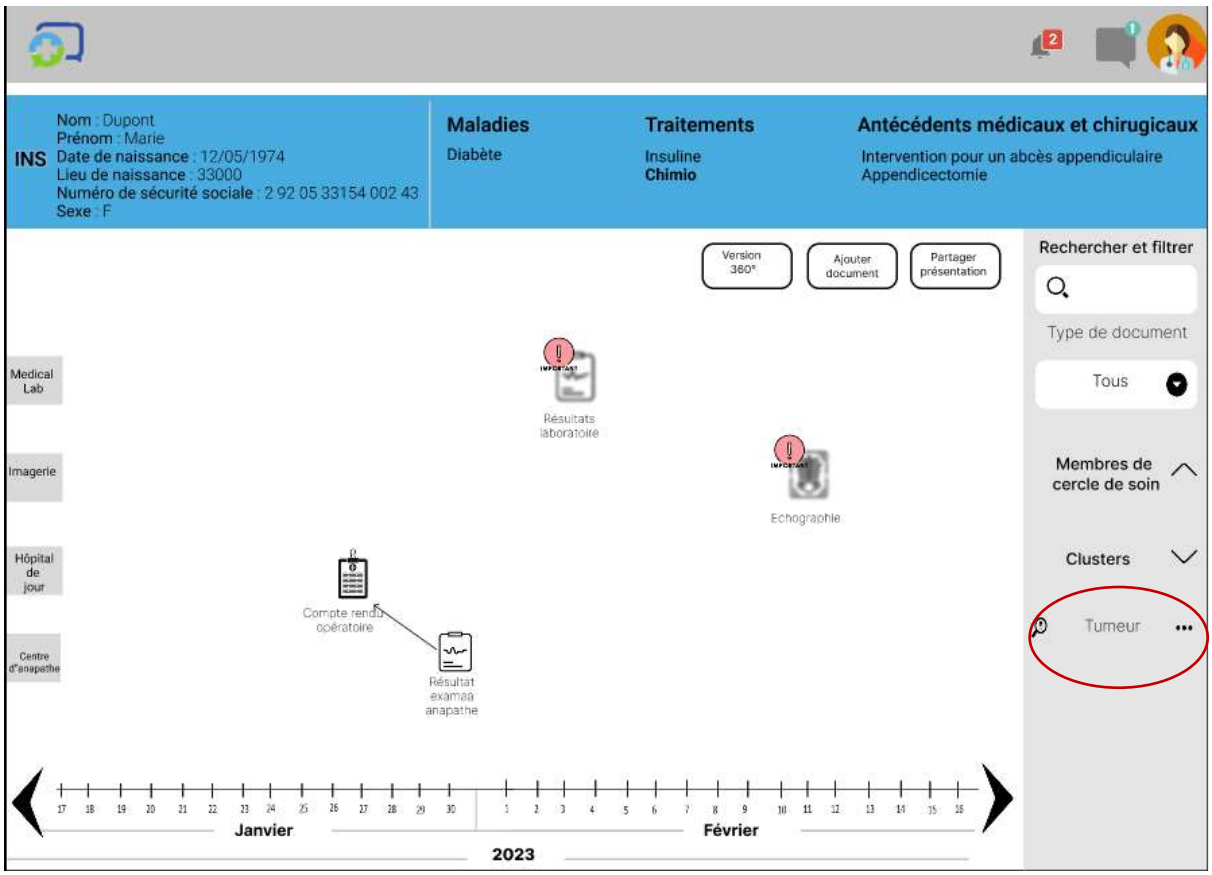


Figure 34 the visualization of the shared clusters and the navigation suggestions

4.4 Conclusion

Through the proposition of the model CaseOverview, our thesis aims to shed light on the possible way to adopt the practice-centered computing approach to create systems that align and respect practices. First, in contrast to conventional EHRs that require care actors to document all their interventions in detail to establish a centralized system enabling integrated access to patient data, CaseOverview acknowledges how care actors carry out their work. Therefore, considering that care actors share documents with their peers to ensure the continuity of care, CaseOverview focuses on including those elements rather than overwhelming a shared tool with an extensive volume of data. Second, instead of developing a novel centralized solution, CaseOverview presents a layered approach that empowers care actors to navigate through the specific content they choose, gather, produce, and search for, using a visualization layer that aligns with their preferred communication tools. Third, regarding data representation within this visualization layer, CaseOverview followed the mantra proposed by Shneiderman (Shneiderman, 2003) as it first gives a broader overview and allows zooming, filtering, and detailing according to the demand.

Then, in contrast to emphasizing or displaying the actual content contained within the documents shared among care actors, CaseOverview facilitates the identification of documents as comprehensive entities that serve as landmarks, highlighting significant events. This approach aims to enhance navigation capabilities, fostering efficient exploration and utilization of the tool. Moreover, diverging from the hierarchical approach that organizes data within folders based on source, time, problem, or goal, CaseOverview grants users the flexibility to customize the visual presentation based on their immediate requirements. As a result, it allows filtering and readjusting the presentation based on the patient's specific situation, the encountered problem, and the potential interaction with other care actors. At the same time, while the traditional EHRs have a static data presentation for all the users, CaseOverview gives two different presentations. First is the comprehensive overview that grants all the care actors the big picture where they can find and spot the various documents highlighting the various care episodes emerging in the patient’s case. Second, the system allows the users to shift to a situated overview that focuses on the documents they produced, received, or selected, which they need to fulfill their local tasks from their own perspectives, preventing them from losing time browsing the comprehensive overview during each encounter with the patient.

Furthermore, given the crucial necessity of preserving the context surrounding shared documents, CaseOverview offers a designated communication space that enables care actors to engage in exchanges, fostering enhanced comprehension and contextualization of the information shared within the diverse medical documents.

Chapter 5: Evaluation

To evaluate the design implications identified from our fieldwork, we translated them into a model of a system called CaseOverview, which we assessed through two iterations. In the first one, we organized a workshop with various care actors to observe and discuss their interaction with the model and collect their feedback, allowing us to review our design implications and enhance our model. We then organized meetings with other care actors to get new feedback and input on the revised model. In this chapter, we explain the objectives of the evaluation study, the method to organize this phase, the method to analyze the collected data, and the results.

5.1 Method

To assess our system model and the design implications, we organized a workshop with various care actors and planned follow-up interviews to have the opportunity to revise the first proposition and enhance it, and then integrate insights into a revised version. Our objective was to assess the extent to which the care actors perceive CaseOverview as suitable for their practices and conducive to obtaining an overview of a patient's case.

Thus, during the first iteration, we organized a workshop to expose the participants to various situations in which they must get an overview of a patient's case to deliver the needed care. Following a scenario-based design (SBD) approach (Rosson & Carroll, 2009), we relied on the data collected during the fieldwork to create four scenarios that presented the different situations where constructing an overview of a patient's case is needed: 1) during the first interaction between a care actor and a patient, 2) during a follow-up encounter, 3) upon problem and emergencies, and 4) during the collective work moments (Details about the scenarios and the used mock-ups in annex n°2).

The workshop (see Figure 35) gathered seven participants (see Table 2): two general practitioners, three nurses, an emergency doctor, and a podiatrist. Four of the seven participants were previously interviewed during the fieldwork. It lasted two hours and a half. We started the workshop with a brief presentation of our understanding of their practices to report the result of our analysis. Then, we used a tablet and a large touch screen to run the various scenarios on the proposed model implemented in Figma prototype. We gave the participants printed copies of the mockups and encouraged them to comment on the various features and make propositions. We were two researchers working to explain the various features and taking notes during the discussions between the participants. We filmed the interaction of the users with the touch screen and audio recorded their conversations. At the end of each scenario, we outlined the participants' perspectives concerning the model, encompassing the features that were deemed beneficial, unclear, or ambiguous. Additionally, we summarized their recommendations to enhance the model.

Figure 35 Evaluation workshop

Then, during the second iteration, we conducted three interviews with a physiotherapist, a nurse, and a general practitioner, who did not participate in the workshop to gather new feedback on the revised version. During those interviews, we used the revised printed mockups (See table 3) and an interactive device to walk through scenarios, exposing the interviewed care actors to situations where they need to get an overview of the patients they follow. During the execution of the various steps, the interviewees were encouraged to comment on the mockups and circle the areas they found pertinent or confusing. Likewise, we recorded the interviews and took notes.

Table 2 List of participants in the two phases of evaluation

Evaluation step	Position	Sector - Workplace
Workshop	General practitioner_1	Salaried - Champagne Sud Hospitals
	General practione_2	
	Emergency doctor	
	Nurse_1	
	Nurse_2	Private practices - Troyes
	Nurse_3	
	Podiatrist	
Interviews	Physiotherapist	Private practices- Troyes
	General practitioner_3	
	Nurse_4	

5.2 Analysis

We transcribed and analyzed the various recordings from our workshop and interviews to better understand participant feedback on how to support achieving an overview of a patient's case effectively. We classified the feedback related to our five implications for design: 1) offering a comprehensive overview, 2) supporting the creation of situated overviews, 3) supporting temporal awareness, 4) supporting social awareness, and 5) offering a problem-based overview. Through our analysis, we also discovered a connection between these themes, as care actors prefer to have the flexibility to switch between a comprehensive overview and a situated one while maintaining their social and temporal awareness. Furthermore, offering a problem-based

overview can enhance the creation and use of situated overviews. In the following sub-section, we will provide a detailed description of these themes.

Table 3 The list of modifications included in CaseOverview between the two iterations of the evaluation

1st version of CaseOverview	2nd Version of CaseOverview
All the care actors can spot and access the details and the full text of the uploaded documents displayed in CaseOverview.	All the care actors can spot the shared documents in the comprehensive overview. However, access to the document's full text is restricted to the one who owns the documents or those who submitted an access request and got permission from the documents' owner.
The comprehensive overview displays the documents that were shared between care actors involved in the patient's care.	The comprehensive overview displays the shared documents and instances representing encounters where the care actors did not generate any document.
Documents in the 2D canvas are represented using different icons to distinguish between their different types.	Documents in the 2D canvas are represented with different icons with the possibility to attach stickers highlighting their relevance and importance according to each care actor.
The y-axis in the comprehensive extended overview (where the overview displays multiple months or years) highlighted all the specialties and institutions involved in the patient's care.	The y-axis in the comprehensive extended overview grouped all the specialties in one line and all the institutions in another one.
Care actors can create and share clusters.	Care actors can 1) create clusters, 2) attach reminders to summarize and add their own notes and observation to the documents included in the cluster, and 3) share the cluster with or without the reminders with the other care actors around the patient.

5.2.1 Offer a Comprehensive Overview

Care actors agreed that having a single tool enabling various actors around the patient to view events constitutes a pivotal progression toward achieving a comprehensive overview and organizing collective care. During the workshop, care actors emphasized the importance of visualizing and identifying various produced documents to help spot trends, follow critical event progress, and create an overview of the patient's case. They welcomed the idea of visualizing and finding everything exchanged around the patient without uploading or documenting information in another system besides the EMRs they currently use. Care actors argued that owning a viewer that facilitates navigation of the various tools would help them encounter interoperability problems between their EMRs and communication channels. Automated feeding would significantly alleviate concerns regarding manual data input and uploading responsibility.

> *"Today, we have a serious burden to find the documents we need or to know the people who treat the patient [...] Another serious challenge is the connection problem between the communication tools that the others use and our software. I have people who send me reports on Mailz, which I cannot connect with my software. Thus, I struggle to send my reports through this channel, and I struggle to download what I receive to put it in my records. For that, I find this proposal very, very innovative. It will avoid many problems concerning who needs to fill what, but it will also allow us to find what we are looking for from what we receive without extra effort to organize and manage the various communication channels."* **General practitioner_3**

The participants agreed that transitioning from a high-level view spanning several months, such as the document cloud presentation, to a more granular perspective focused on a particular month would be advantageous when a broader comprehensive understanding is desired. Additionally, they found the 360° vision helpful in getting insight into the case of patients they meet for the first time or those they do not see often. Care actors appreciated the function of discussion around documents to gain context into their content and the ability to attach pertinent comments.

> *"We [nurses with private practices] are responsible for monitoring patients at home, so we periodically check the blood test to track the progress. Yet, as soon as the patients enter the hospital, we struggle to keep up with our follow-up after their discharge as we never receive reports or laboratory results that describe the analysis made during the hospitalization. We never know how to adapt our follow-up. Having this 360° view will at least allow us to see that there were blood tests that we can request because they are essential for our care."* **Nurse_4**

Regarding open access to all care actors to the content of documents, care actors argued that it might cause some issues related to medical secrecy. Therefore, they suggested granting the document owner the possibility to provide unrestricted access to all stakeholders or limiting access to specific individuals upon request. Care actors also discussed the role of the patient in offering these permissions and the need to include the patient in the visualization to expand its content.

Finally, the care actors emphasized the importance of fixed panels presented in the visualization, such as the general information panel and the one displaying the care actors around the patient. However, they criticized the feature that allows feeding the top panel with general information from the discussion around the patient, arguing that feeding a medical record with data about the patient requires following rules fixed by the legislation and keeping the data in a health data host[34].

In summary, we argue that offering a comprehensive overview of the patient's case may ease and enhance the understanding of the patient's case. Yet, as the access to details within this comprehensive overview depends on each care actor's responsibilities and position, we suggest that a system that supports achieving an overview within an integrated care context should offer a multi-level comprehensive overview. First, the system should afford overview+details (Plaisant et al., 1994) options allowing users to navigate from a general overview to a detailed one according to their needs. Second, the degree of proposed details needs to take into consideration the role and the access permission of the various users.

5.2.2 Support the Creation of Situated Overviews

While obtaining a comprehensive overview of a patient's case is advantageous for understanding their condition holistically, it may not always be desirable. Care actors argued that shifting from the 360° view to their situated overview would allow them to focus on the issues they are treating. Therefore, the feature permitting them to regroup the documents they produce and receive with the possibility to select other documents to enhance their situated overviews was deemed valuable. The emergency doctor claimed that such a feature, which considers their needs, would provide them with an organized library where they can easily find what they are looking for.

[34] An organization wishing to host health data must be HDS certified (health data host), certification which aims to protect this sensitive and personal data. Its objective is above all to protect patients against any leakage, alteration or loss of their data. Thus, the host must ensure the integrity, compliance and traceability of personal health data

Moreover, care actors confirmed that they generally start by checking what they have before searching to extend their overview.

> *"That's the difference with the DMP, which stores everything in the same hierarchy where we feel lost when we look for something. On the other hand, this system gives us a more organized library that facilitates our research, corresponds to our needs, and imitates how we organize our documents."* **Emergency doctor**

Furthermore, Care actors discussed the necessity to afford the possibility of adding documents using their mobile, for instance, by using their camera, which allows them to supplement the system with more documents rapidly. For instance, the podiatrist highlighted that they would prefer to visualize images they took to follow the progress of foot rehabilitation alongside the other documents. Furthermore, they suggested providing the possibility of creating sticky notes that they would attach to the documents within their situated overview to remind themselves of the decision made upon the review and the selection of those documents.

In addition, care actors appreciated the interaction-based navigation. They argued that this feature would allow them to enhance their situated overview and avert any potential loss of time incurred while navigating through the comprehensive one. According to general practitioners, this particular feature will ensure prompt retrieval of relevant and related documents, thereby allowing for a greater emphasis on patient consultation.

> *"It will be very practical if the system suggests documents similar to what we usually look for and use. I mean, nowadays, we spend time moving from one folder to another and clicking many times to find the information we need. Also, spotting the documents related to those we are checking at a certain moment will make it easier for us to find more relevant elements and understand the patient cases."* **General practitioner_3**

However, care actors expressed concern about the use of the proposed tool. They argued that they will still be using their EMRs to record their intervention, and it may become overwhelming to use another tool. However, the participants found our model more practical because it streamlines the organization of obtained documents and provides a more comprehensive overview, resulting in timesaving advantages. Thus, the emergency doctor reflected on the effectiveness of adopting such design decisions to enhance the features proposed by the DMP. They argued that shifting from a comprehensive overview to situated overviews based on the need of care actors would facilitate and promote the system's use.

To summarize, care actors create situated overviews focused on their information needs. Therefore, a system that supports achieving an overview of the patient's case needs to support switching from a comprehensive overview to a situated overview that focuses on the care actors' needs. This situated overview should allow users to review documents they own, receive and select.

5.2.3 Support Temporal Awareness

The system's most crucial aspect is monitoring the events and activities surrounding a patient. All care actors agreed that identifying various encounters allows them to contextualize and correlate their actions with those happening concurrently. They also emphasized the need to visualize encounters involving document creation and those without any documentation.

> *"There are actors who do not give documents, so we cannot see them or know if the patient has had any interactions with them, the housekeepers, for example. Knowing if the patient receives help for particular tasks is important. It makes it easier to understand his case."* **Nurse_2**

Identifying both encounters in the visualization helps care actors understand the patient's care episodes and assess adherence to personalized care plans. For instance, general practitioners and emergency doctors often prescribe care plans and refer patients to physiotherapists. Knowing whether the patient followed the plan and attended all prescribed sessions is vital for tracking progress and identifying factors contributing to care plan failure.

> *"I mean, for the care pathways, it is very important to know the presence and the non-presence to be able to assess the patient's progress. In this case, it would be nice if we could see the scheduled visits made or not even without documents."* **General practitioner_1**

However, during mock-up revisions, interviewees agreed that visualizing every visit as a landmark is less critical than illustrating the scope of the care provided. They proposed allowing care actors to indicate the beginning and end of a care episode, such as a nurse administering anticoagulation drugs, and attaching summaries outlining actions and their frequency.

Care actors also emphasized the need to identify critical documents highlighting significant issues, proposing features that generate alerts upon uploading such documents. A discussion arose regarding alert recipients and determining which documents warrant more attention. The recommendation feature was suggested for alerting purposes, allowing users to add urgency stickers and notes explaining the document's importance.

In conclusion, care actors agreed that maintaining temporal awareness of care episodes and identifying critical events is essential for improving their understanding of a patient's case and promoting timely, appropriate care. A system designed to provide an overview of a patient's case should incorporate features that offer insights into event occurrences and emphasize those requiring urgent attention.

5.2.4 Support Social Awareness

Recognizing the various care participants involved in a patient's treatment is crucial for comprehending the treatment events and care plans. The participants emphasized the importance of a fixed panel depicting the care circle and a y-axis illustrating the document's origins for contextualizing and improving the patient case overview. They also stressed the significance of identifying key care actors listed at the top of the y-axis.

> *"Knowing who sees the patients more often is a very important feature. Usually, it is the assigned physician, but if they see someone else, it's good to know as it gives us an idea of the proposed care plan."* **General practitioner_3**

Although the care actors found value in the y-axis, they expressed concerns about the potential overcrowding of information. They proposed displaying all involved specialties on separate lines in the detailed short-term visualization. When expanding the visualization for a broader overview, they recommended consolidating the specialties on a single line and grouping the various departments within their organizations. This approach would enable users to determine whether patients are consulting specialists or admitted to medical facilities. Furthermore, One general practitioner suggested that connecting descriptive keywords to the specialists' lines would aid in understanding the types of specialties involved.

Additionally, care actors voiced the need to know the source of the general information displayed in the top panel, as its absence could lead to visibility and trust issues. They recommended providing details about the creation date and information origin.

"*Having general patient information pinned at the top is fine. But we need to know who pinned this information and when. Otherwise, we will not know if the information is relevant or up-to-date, and consequently, we will not use it*" **General practitioner_1**

To summarize, acknowledging the care circle treating the patient is crucial information that deepens the understanding of the events occurring and the followed care plan. Therefore, we suggest that the system aiming to support achieving an overview of the patient's case needs to maintain the user informed about the actors participating in the treatment and the origin of the information displayed within the overview display.

5.2.5 Offer a Problem-based Overview

Monitoring and addressing the various issues in a patient's case are central to medical practice. Participants expressed appreciation for the ability to create and visualize clusters, which they deemed essential for effective follow-ups. They believed that classifying documents would simplify identifying significant issues and provide a comprehensive overview of the patient's case. They also emphasized the importance of considering synonyms, which could appear differently in various documents yet refer to the same issue. Linking these synonyms to a unified meaning would facilitate information retrieval and improve cluster content.

"Creating custom clusters is great. It will allow us to focus on the issues we want to deal with first. It will save us a lot of time looking for these elements each time. What I like to have with this is the possibility of attaching post-its and notes to remember the content of these clusters and my observations quickly." **General practitioner_1**

Participants welcomed the prospect of receiving notifications about new documents relevant to the created clusters, allowing them to update and expand information about the issues they were monitoring. They also explored the potential benefits of automatically classifying documents upon upload to generate clusters that inform about critical issues.

Care actors concurred that a problem-based overview would support cooperative work. While each care actor might create unique clusters reflecting their perspective and treatment strategy, sharing these clusters fosters a shared understanding and facilitates cooperative efforts in addressing medical issues. They suggested the addition of notes to clusters to explain their creation and inform other care actors of the issues requiring collective work.

An emergency physician and a general practitioner noted that these functionalities would significantly enhance cooperation within integrated care pathways. Creating clusters for each addressed issue and involving relevant care actors would enable collective monitoring of pathway progress and streamline care plan organization.

"Creating and sharing clusters will facilitate the monitoring of care pathways. I mean, each cluster can be created for a certain pathway, diabetes, for example. For patients with many problems, we will have many pathways and, accordingly, many clusters. Then, sharing those clusters with the people who participate in the pathway will help all the participants get information about who participates and how often. Also, they can consult the documents to see what's happening, and we can communicate afterward to organize and advance the care plan." **Emergency doctor**

To summarize, organizing the created situated overview around the problems treated is mandatory to spot the critical issues and allow the care actors to identify the possible interconnection between those issues. Therefore, we argue that a system that supports achieving an overview of the patient's case needs to consider situated problem-based presentations to help care actors focus on the issues they manage. Similarly, we argue that some problems need to be addressed collectively. Therefore, the system should allow sharing these problem-based presentations among the cooperating actors to foster cooperative efforts.

5.3 Conclusion

Our assessment study underscored the value care actors place on a system that offers a comprehensive view of a patient's case. The study emphasized the necessity for care actors to have the possibility to switch from a holistic, comprehensive overview to a situated and context-specific overview. Additionally, it validated our design considerations, suggesting that time, source, and problem should be linked when presenting medical documents in the overview.

However, despite being unable to test CaseOverview in a real-world scenario, care providers expressed concerns about using this system alongside their existing tools. One suggestion was to incorporate the design principles showcased in CaseOverview into the centralized systems advocated by the government, aiming to foster and enhance inter-organizational cooperation.

Chapter 6: Conclusion

Inter-organizational cooperation is encouraged to ensure coherence and consistency among various activities carried out by stakeholders from various companies within complex ecosystems (Mervyn et al., 2019). Within this context, awareness is essential to encounter the fragmentation of actors and information. The research work presented in this thesis discusses the significance of achieving an overview of a patient's case to promote awareness and foster cooperation in the context of integrated care. We have presented a case study in Aube County as an example of concrete inter-organizational cooperation. The analysis of our fieldwork allowed us to demonstrate that supporting overviews by keeping, archiving, classifying, and displaying the fragmented data in a unique system, as it is often proposed, does not align with care actors' practices (chapter 2). On the contrary, to bolster the construction of an overview through a technological solution, we have adopted a practice-centered approach (Schmidt, 2018) to 1) investigate how overviews are achieved by the various care actors involved in an integrated care context and 2) Inform the design of technologies to support existing practices thanks to this understanding.

We conducted a qualitative study to discover the various challenges hindering cooperative efforts and the current practices that allow care actors to overcome these challenges to build an overview of patients' cases. Hence, we identified the practices related to the collection and distribution of a patient's medical data to surmount fragmentation, along with the varying strategies enabling each care actor to develop an overview of a patient's case to guarantee the harmony of their actions with other actors involved in the patient's care. Moreover, we examined the obstacles impeding these practices (chapter 3).

Based on those findings, we formulated the design implications of a system supporting building an overview of the patient's case within an integrated care context (Section 4.1). Adopting scenario-based design, we translated those design implications into mock-ups and scenarios of a system, CaseOverview. CaseOverview illustrates the possible way to develop such an overview system (chapter 4). We conducted an evaluation study based on the scenarios we have defined based on our empirical work; we organized a workshop followed by a series of interviews to get the feedback of the various care actors on the design implications and their proposed implementations (chapter 5). In the coming sections, we synthesize the main contributions of our work, its limitations, and some perspectives.

6.1 Contributions

Our research work offers empirical, design, and instrumental contributions.

6.1.1 Empirical Contributions

The empirical findings presented in section 3.3 and section 5.2 answer our first research question: **How *is an overview achieved by the various stakeholders involved in an inter-organizational context?***

i. Building an Overview is a Dynamic Individual Practice

Overcoming data fragmentation and ensuring awareness is mandatory to allow the people involved in inter-organizational cooperation to fulfill their tasks. As such, each person develops distinct dynamic strategies to construct a situated overview that satisfies their information

requirements and provides them with insights into the contextual framework of their work. In IC, each care actor develops their overview of a patient based on their perspective, needs, and communication channels. Therefore, they produce information to be able to track the progress of their activities. Then, they are able, when a particular situation arises, to search for it and to select the information that relates to the situation they are handling. In other words, those strategies employed to create an overview evolve with the situation they encounter and the different healthcare episodes the patient is going through.

We observed that care actors build these situated overviews by using the patient's information received upon referral completed by the traces of their interventions. When confronted with substantial information, they select the relevant information and dismiss the rest. Subsequently, when issues emerge, they search for and incorporate additional information to contextualize and enrich the overview. Moreover, each care actor's degree of comprehensiveness depends on their position and role within the overall care activities. Therefore, some care actors, such as the assigned physician, will generally have a comprehensive overview of the patient's case. In contrast, specialists and paramedics will build an overview of their problems.

ii. The Overview is Built on Shared Documents and Interactions

The efficient and effective exchange of information across diverse organizations relies upon the pivotal role of shared documents. These documents serve both as sources of information and landmarks to track the progress of the activities. Consequently, these documents' collection, selection, and storage constitute the fundamental building activities that enable stakeholders to construct their situated overview.

In our case, care actors achieve an overview by seeking documents that provide a broader perspective rather than the data shared in the patient's file. Moreover, to contextualize, expand and enhance this overview, care actors interact with each other. Along with enhancing the understanding of a case, interactions also play a central role in elaborating an overview. Interaction enables the identification of key documents that must be selected and included in the overview, thereby enabling a prompt response to the various care episodes.

Medical documents are then the building blocks of a case overview as they depict the care episodes of a patient and the care actors who took part in those episodes. Thus, accessing those documents supports care actors' social and temporal awareness. These building blocks are selected and interpreted through interaction among the various care actors.

iii. The Overview is Used Differently according to the Various Purposes

Situated overviews are used differently depending on the situation care actors face: (1) When they meet a patient regularly, care actors opt for chronological navigation to explore their patient's case progress. (2) When an issue arises, care actors look for documents depicting similar issues and those written by the other care actors treating similar problems, so they adopt problem-based navigation. (3) When they interact with another care actor who recommends a document or when they review a document that references other documents, an effort is made to restructure the overview to integrate and comprehend the new documents.

6.1.2 Design Contributions

We derived design implications from our empirical findings. Those design implications answer our second research question: ***How can we use this understanding to inform the design of technologies to support existing practices?***

1. ***Offer a Comprehensive Overview at Different Levels***

Offering a comprehensive overview of a patient's case is one way to overcome fragmentation and provide care actors with sufficient information about the care trajectory of a patient. However, access to detailed information depends on the care actor's role and position in the patient's care pathway. Therefore, a system that supports achieving an overview within an inter-organizational cooperation context should offer a multi-level comprehensive overview. First, the system should allow users to switch from a general overview to a focused one. Likewise, as not all care actors have the same status, the system should allow them to decide which documents could be accessed at the focused level.

2. ***Support the Building of a Situated Overview***

Creating a situated overview enables care actors to choose the many patient-related documents that help them carry on their day-to-day activities and deliver coherent care. Therefore, a system that fosters establishing an overview within the context of inter-organizational cooperation must facilitate the transition from a comprehensive overview to a situated overview. Offering a situated overview emphasizing the documents each actor owns, receives, and selects will give them adequate awareness to carry out their tasks.

3. ***Support Awareness***

Tracking the evolution of activities and occurring events and identifying the care actors participating in those events allows care actors to support awareness, a prerequisite for inter-organizational cooperation. A system supporting the building of a case overview should ensure that all the care actors involved in the case and the provenance of the information presented in the overview can be identified. Moreover, issues that necessitate immediate attention should also be easily identified.

4. ***Offer a Problem-based Overview***

Centering the overview on problems allows care actors to spot the core issues, follow their progress, and coordinate with others to treat them. Therefore, a system facilitating the building of a case overview should allow the creation of situated problem-based visualizations that assist each user in focusing on the issues they manage. At the same time, as some issues must be addressed collectively, the system should enable sharing these problem-based presentations among cooperating actors.

6.1.3 Instrumental Contributions

Considering the care actors' practices and the derived implications for design, we offered CaseOverview as a technological solution that illustrated how the design implications could be translated into a system. CaseOverview integrates the care actors' existing communications channels and offers a visualization layer to browse shared content. Our suggestion aligns with previous work in CSCW, requesting the need to align with care actors' current artifacts (ex., systems, tools, etc.), as argued by (Bødker & Klokmose, 2012). CaseOverview also takes care of documents as a whole instead of considering only the data they convey.

Our goal with CaseOverview was not to develop a new system but instead to use CaseOverview to draw the attention of the French institutions and the health informatics community to the necessity to adopt a practice-centered approach to design systems that fit with care actors' practices, needs, and current artifacts. Moreover, our work invites the health informatics community to explore ways to design systems to overcome fragmentation through case overview.

6.2 Limitation and Future Work

Several limitations pertain to this work.

1. Our case study focused on integrated care as an example of inter-organizational cooperation. However, while this case study allowed us to explore the existing practices to achieve an overview and the centrality of documents and interaction, further investigations are needed to discover other elements influencing or changing how overviews are achieved in other inter-organizational contexts, for instance, in crisis management.
2. While CaseOverview aims to facilitate the navigation of shared documents, it becomes apparent that this task is challenging when the number of documents pointed in response to a query spans a significant period. As such, it is imperative to devote further attention to the filtering process to enhance the finding of the most pertinent elements.
3. As we mentioned in section 4.2, extracting documents from existing channels, retrieving their metadata and content, and classifying them into their corresponding types, encounter many technological challenges. Therefore, an additional investigation has to be done to build an adequate architecture that overcomes the various challenges we have identified.
4. Based on French policy, we could not deploy any system in real settings. Thus, we could only assess feedback on the principles, but we could not study its appropriation.

Henceforth, we endeavor to work further with the National Health Agency (ANS) and the Regional Support Group for the development of E-Health (GRADS), which bear the responsibility for certifying and developing Health Information Systems (HIS) that foster cooperation among care actors. The aim is to transfer our findings to ensure to inform the design of future systems in line with the goals of the MaSanté 2022 strategic plan. Moreover, we think further work is needed to investigate the role of interaction and how to support it in this overview's achievement process.

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Annexes

Annex 1: Informed consent

Accord de participation au projet de recherche CareKnot

Présentation

Le projet CareKnot vise à proposer de nouveaux modèles pour la conception de systèmes d'information collaboratifs dans le domaine médical. Le projet s'inscrit dans les efforts menés pour atteindre les objectifs de plan national stratégique de santé (SNS) 2022, notamment pour suivre la loi n° 2019-774 du 24 juillet 2019 relative à l'organisation et à la transformation du système de santé qui vise à favoriser la coopération entre les acteurs et les métiers de la santé.

Afin de comprendre les pratiques actuelles de travail entre les acteurs de l'hôpital et de la ville, des entretiens semi-directifs sont menés par des chercheurs de l'UTT (entre trente minutes et une heure), sur le lieu choisi et au moment choisi par la personne interviewée, avec les professionnels de santé (médecins spécialistes, médecins traitants, infirmiers, aides-soignants) exerçant au niveau de l'hôpital ou de la ville, ainsi qu'avec les équipes administratives (secrétaires, assistants…).

Ces entretiens nous permettront de :

- Comprendre les pratiques existantes, et l'usage d'outils existants en matière de coopération entre les professionnels de santé de (au sein de l'hôpital et avec la ville).
- Suivre le déploiement dans l'Aube de Parcéo, initiative régionale pour soutenir cette coopération entre acteurs de la prise en charge. ;

Ces entretiens seront enregistrés et numérisés. Ils seront anonymisés et leur accès et leur traitement (analyse qualitative, codification) sera restreint aux membres de l'équipe CareKnot : Rahma Marref (doctorante, UTT), Khuloud Abou Amsha (Maître de Conférences, directrice de thèse, UTT), Myriam Lewkowicz (Professeur des Universités, co-directrice de thèse, UTT). Des extraits (anonymes) de ces entretiens ainsi que leur analyse pourront être utilisés dans des publications scientifiques des membres du projet.

Leur analyse nous permettra de :

- Proposer une stratégie d'intégration des nouveaux outils respectant les pratiques actuelles et permettant une réelle mise en œuvre de la coopération.
- Produire un modèle duplicable dans les autres départements de la région Grand Est, voire plus largement.

Accord de participation

Je soussigné(e)…… déclare accepter que les données recueillies par l'intermédiaire d'un entretien individuel puissent faire l'objet d'un traitement informatisé dans le respect des données personnelles.
J'ai été informé(e) que cette étude sera conduite conformément à la législation française en vigueur.
J'ai été informé(e) :

- De la finalité du traitement des données ;
- Qu'aucun traitement informatisé ne sera réalisé sur des données nominatives mais sur des données anonymisées;
- De mon droit d'accès et de rectification à ces données tant que la base de données n'est pas codifiée ;
- Que les données anonymisées seront détruites (non stockées) à la fin de l'étude.
- Que les données codifiées pourront être utilisées dans le cadre de publications scientifiques.

Je connais la possibilité qui m'est réservée de refuser mon consentement ou de le retirer à tout moment, quelle qu'en soit la raison, sans avoir à la justifier, et sans aucun préjudice pour moi-même. Mon consentement ne décharge en rien les organisateurs de la recherche de leurs responsabilités. Je conserve tous mes droits garantis par la loi.

J'ACCEPTE DE PARTICIPER A CETTE RECHERCHE DANS LES CONDITIONS PRECISEES DANS CE DOCUMENT.

Le……..

Signature de la personne participant à l'étude
Précédée de la mention « lu et approuvé »

Annex 2: The evaluation study's scenarios and mockups

Scénario 1 : Première visite avec le patient

a. Avoir un vu d'ensemble sur la patiente

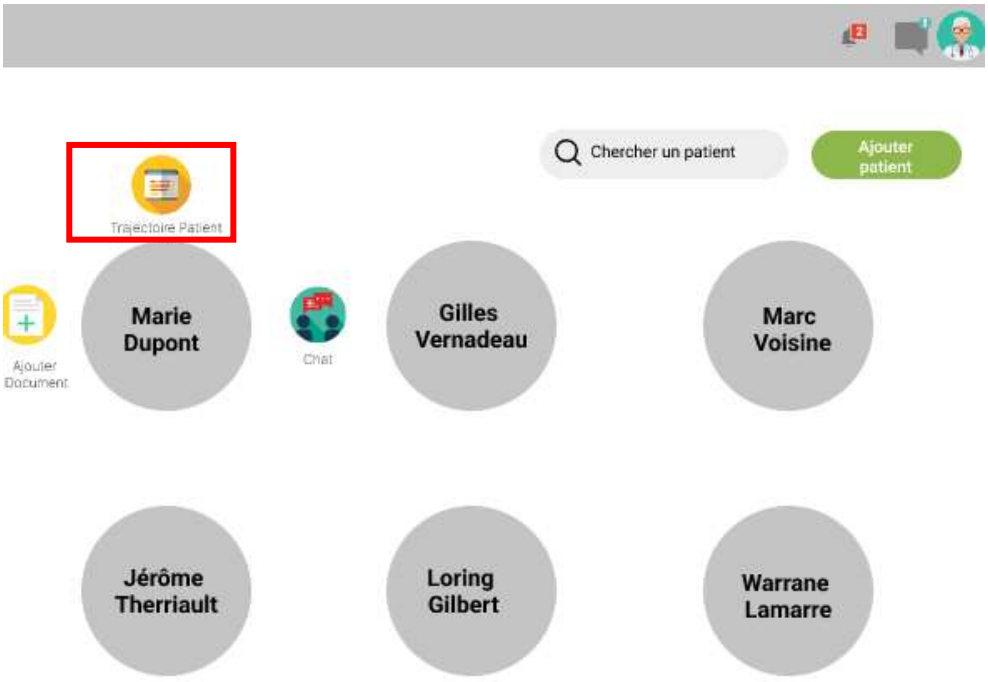
Une fois identifié Dr. Traitant voit une liste de tous ses patients, pour ajouter Mme Dupont,

1. Dr. Traitant clique sur le bouton **Ajouter patient**
2. Dr. Traitant met le nom prénom et n° de sécurité sociale de Mme Dupont et clique sur le bouton **Valider**

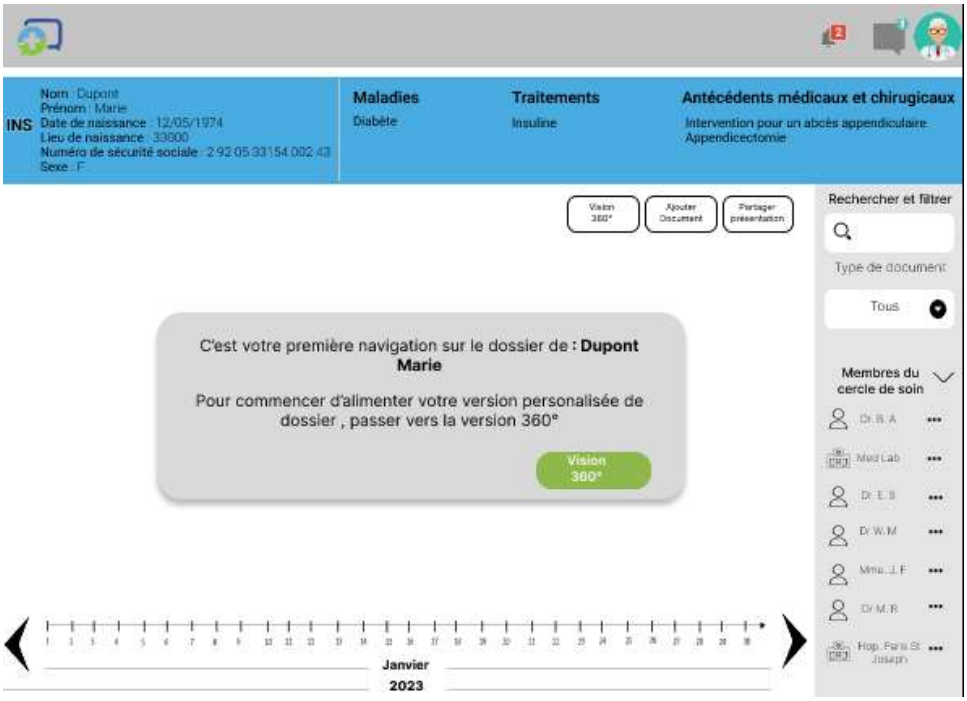
3. Le système affiche à Dr Traitant les patients avec des informations similaires il clique sur le bouton **valider**

4. Dr. Traitant clique sur le nom de **Mme Dupont**

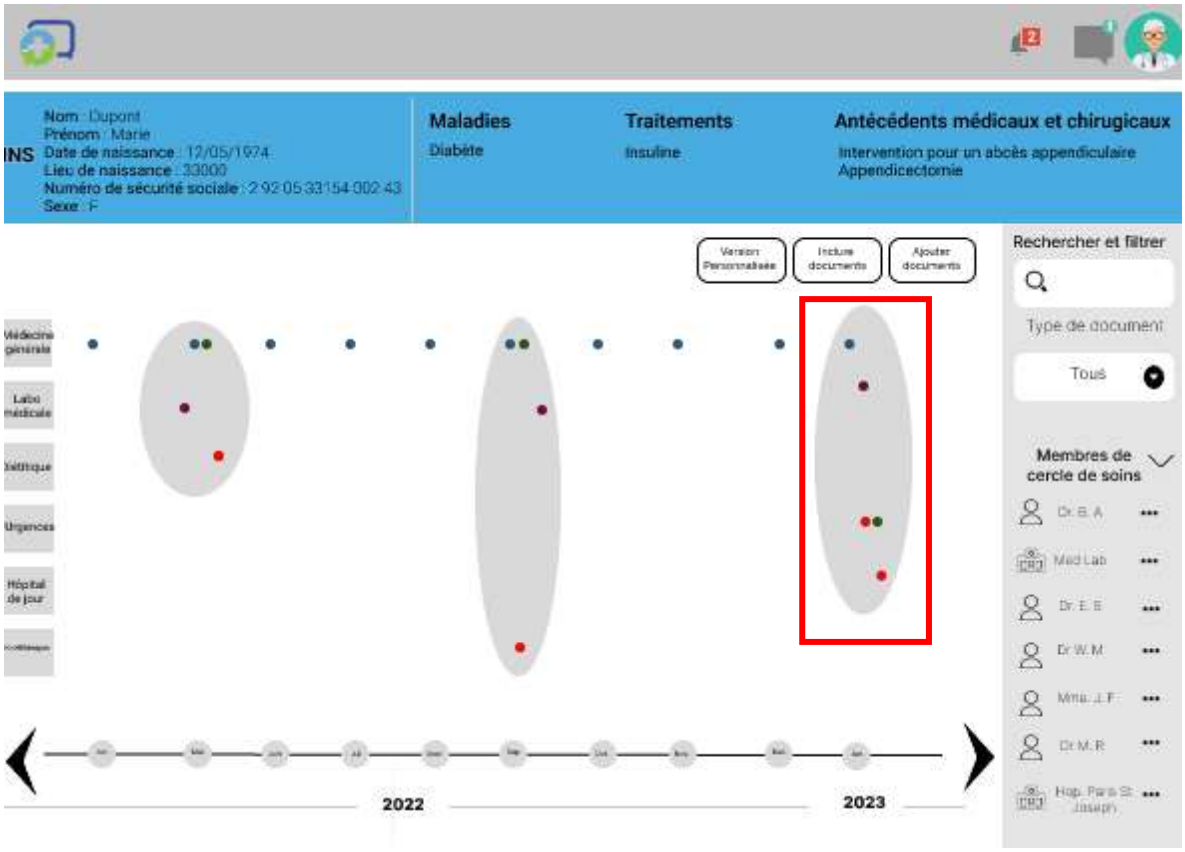
5. Il clique **Trajectoire patient**



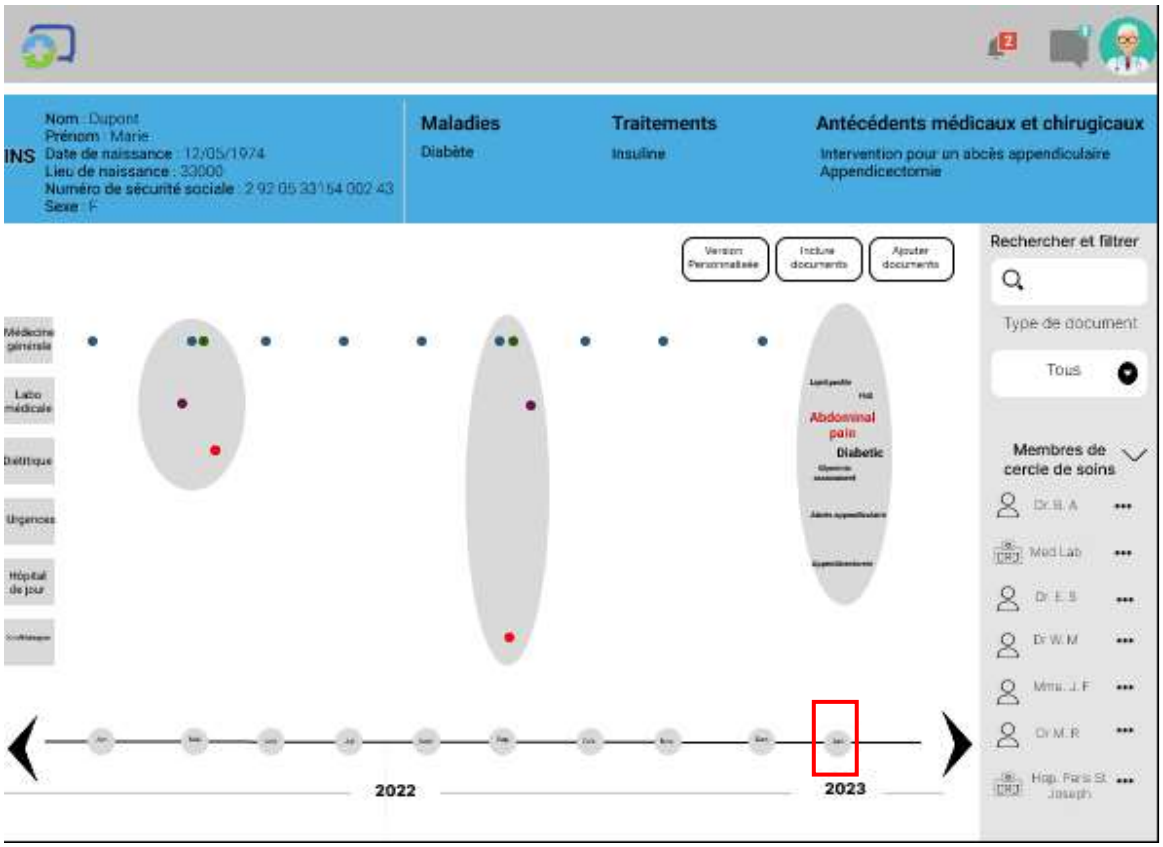
6. C'est la première fois qu'il voit Mme Dupont alors Il clique sur **vision 360°**



7. Le système montre des nuages des documents échangés par les professionnels de santé de Mme Dupont

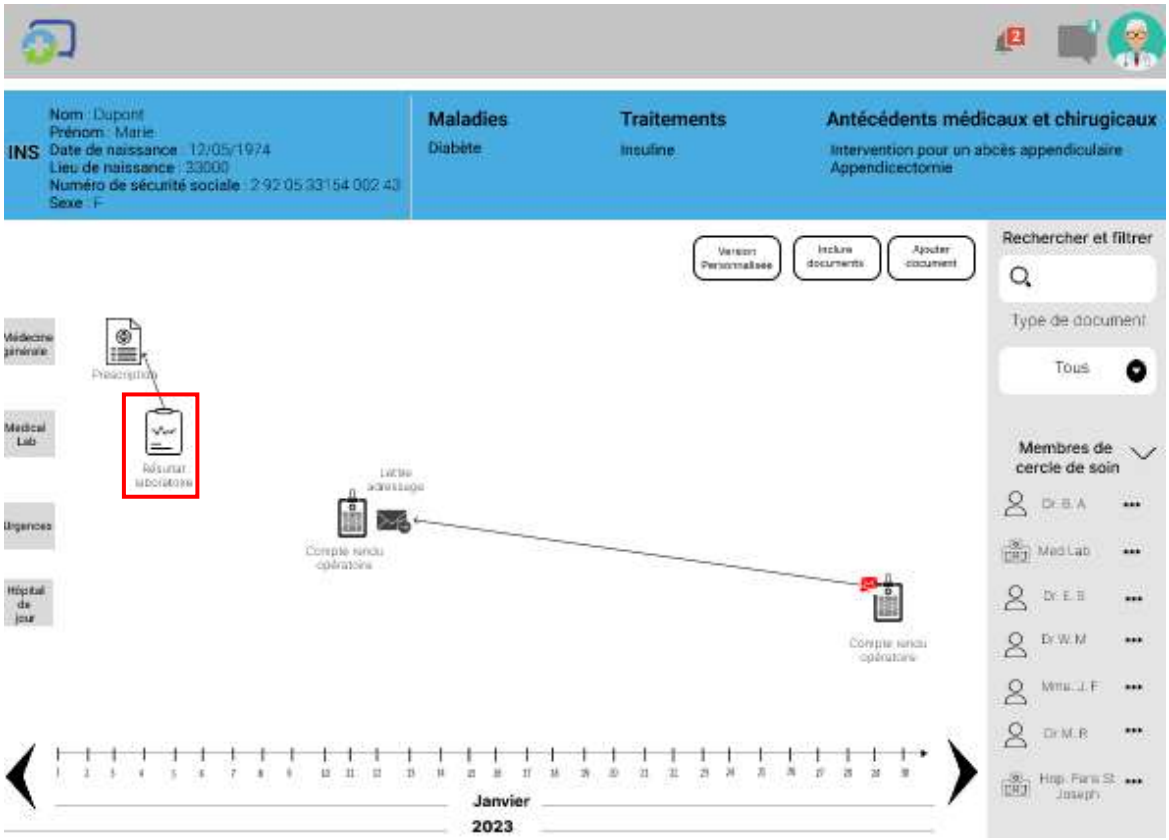


8. Il clique sur le dernier mois pour voir les documents de ce dernier

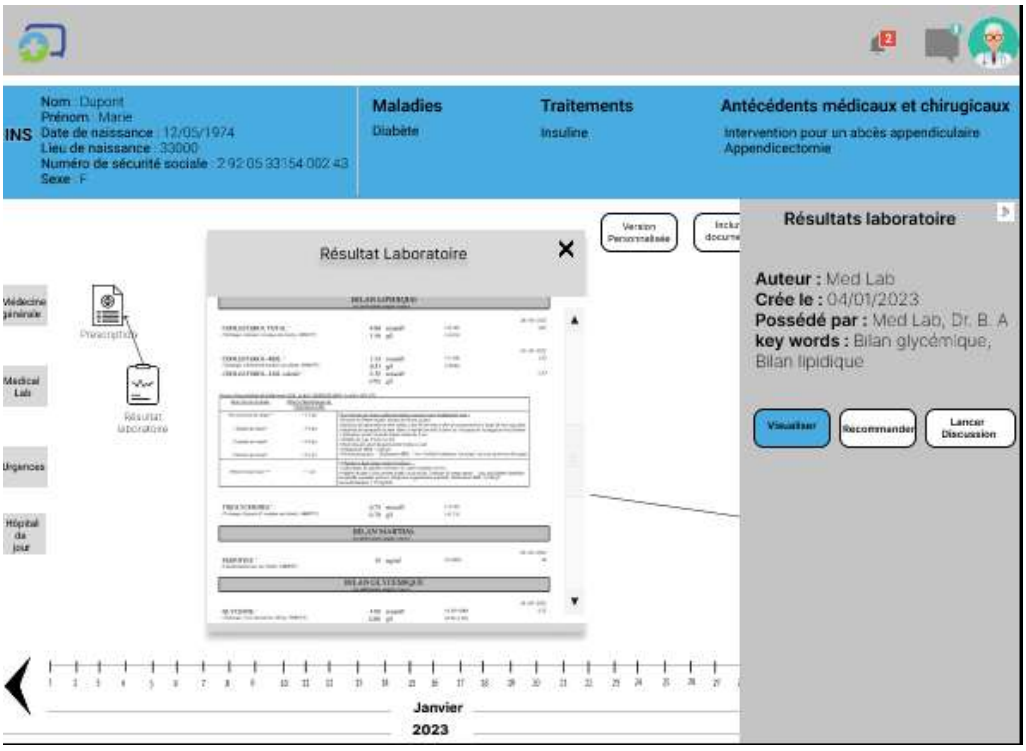


b. Visualiser un Document

1. Il clique sur le document « Résultat laboratoire »



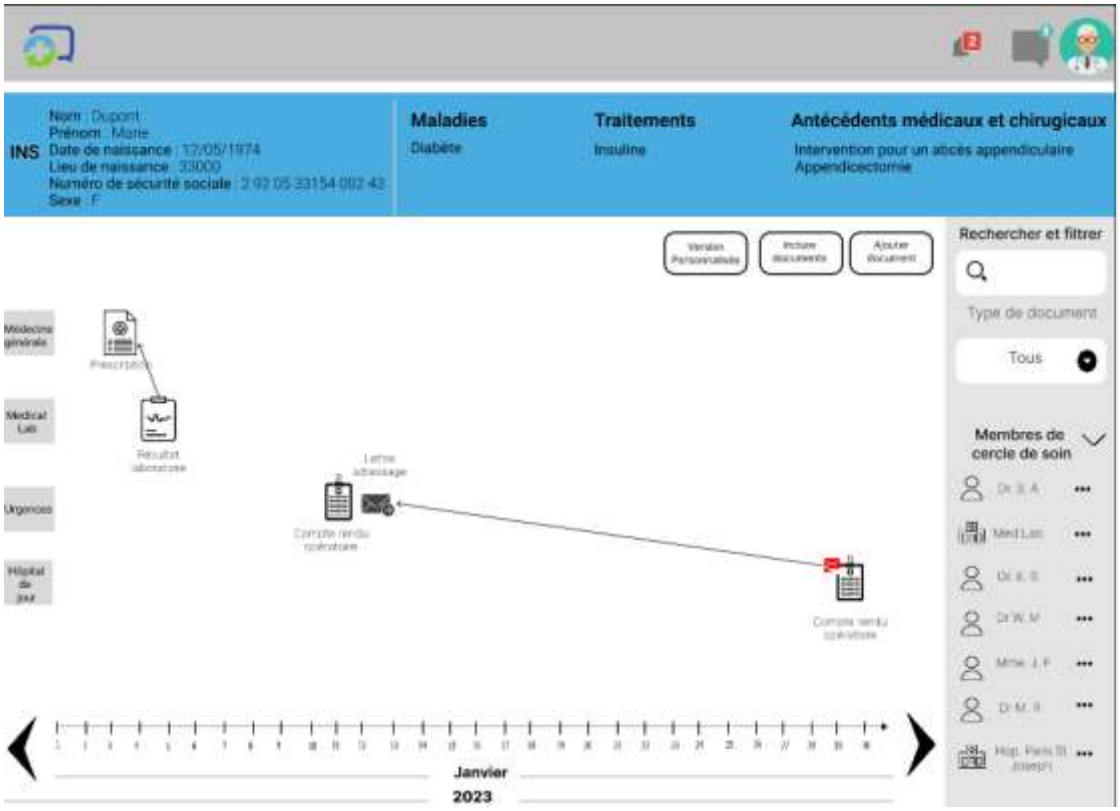
2. Il clique sur visualiser



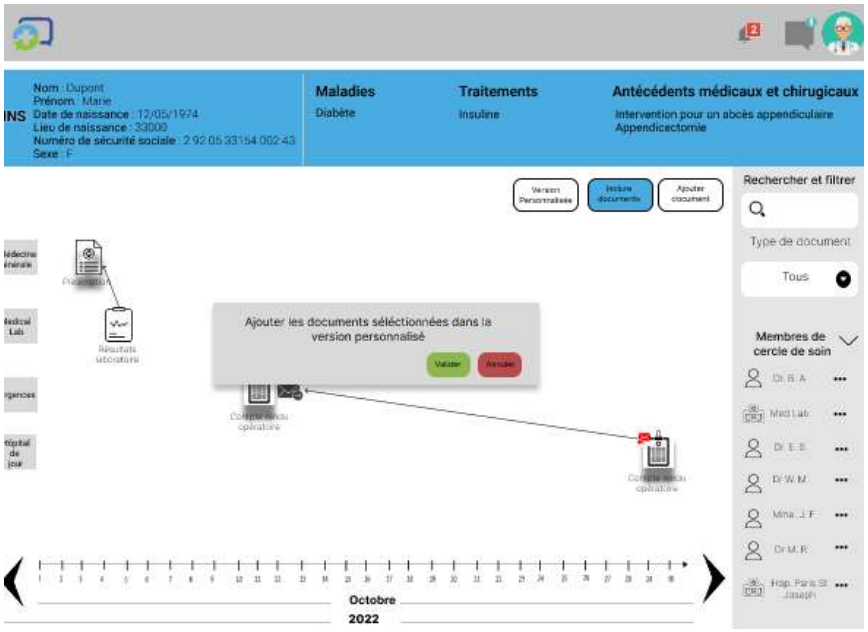
3. Il ferme le document en cliquant sur 

c. Personnaliser la version de dossier

1. Il clique sur « Inclure document »

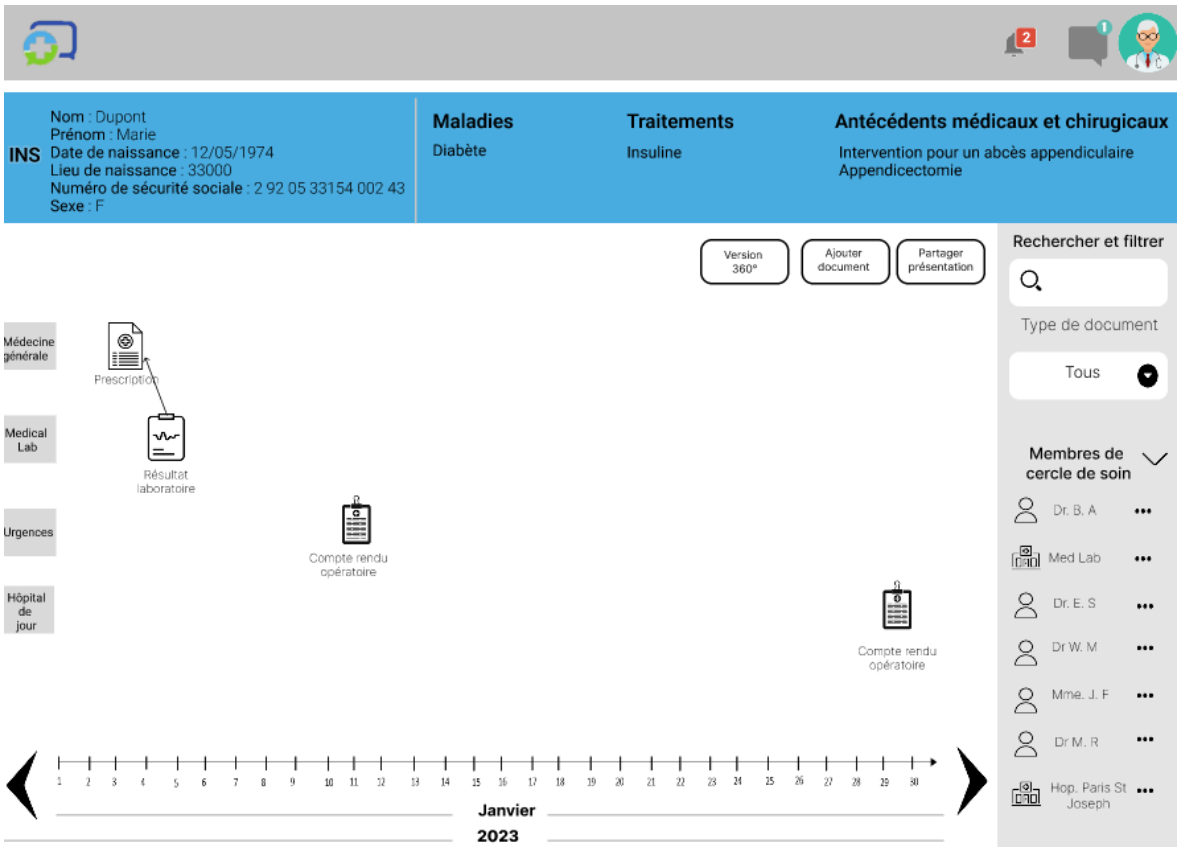


2. Il sélectionne les documents et clique sur Valider

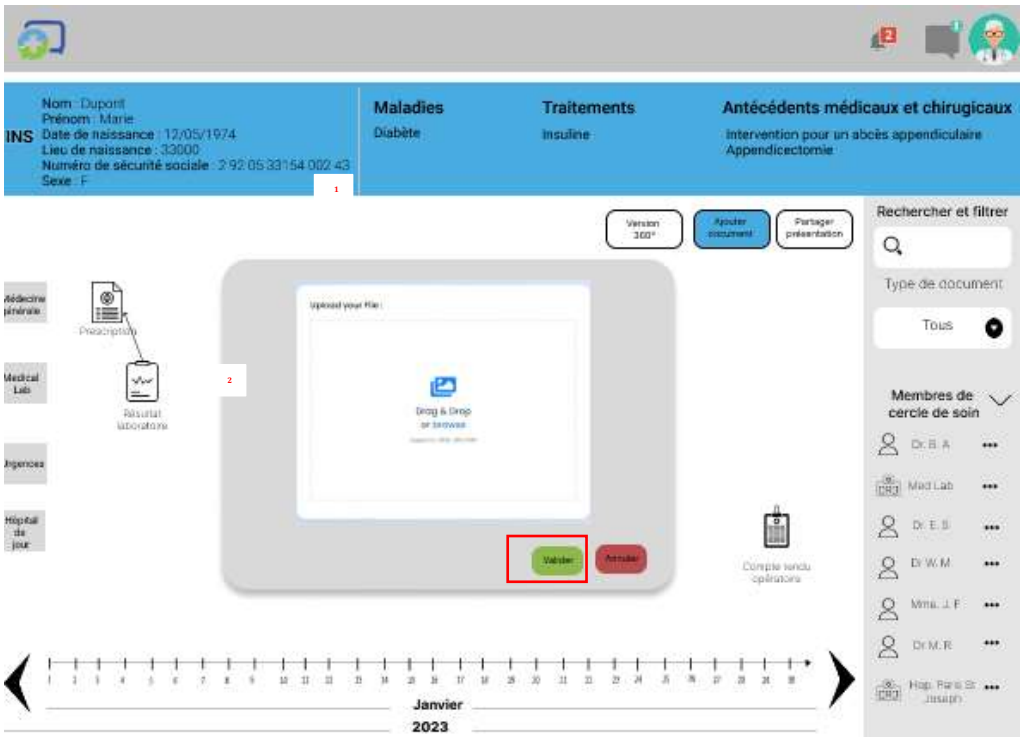


d. Ajouter Manuellement un document

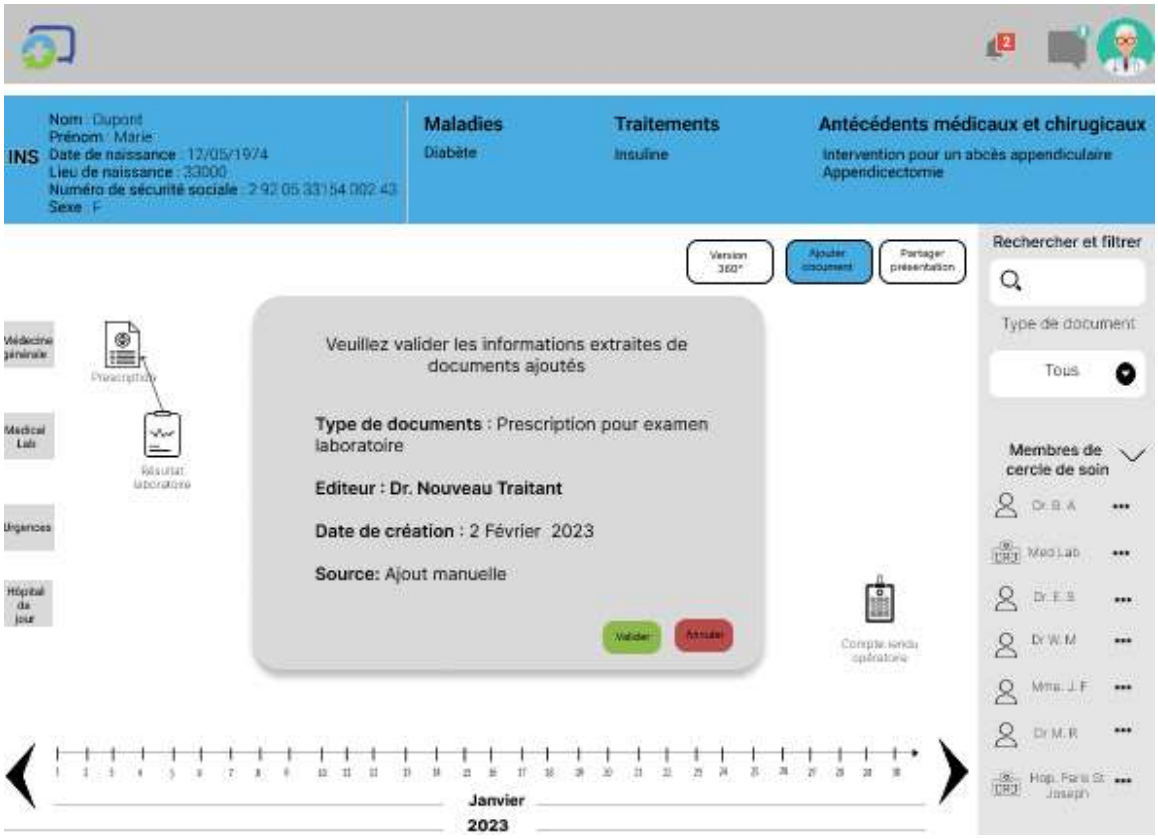
1. Il clique sur « Ajouter Document »



2. Il clique sur Valider



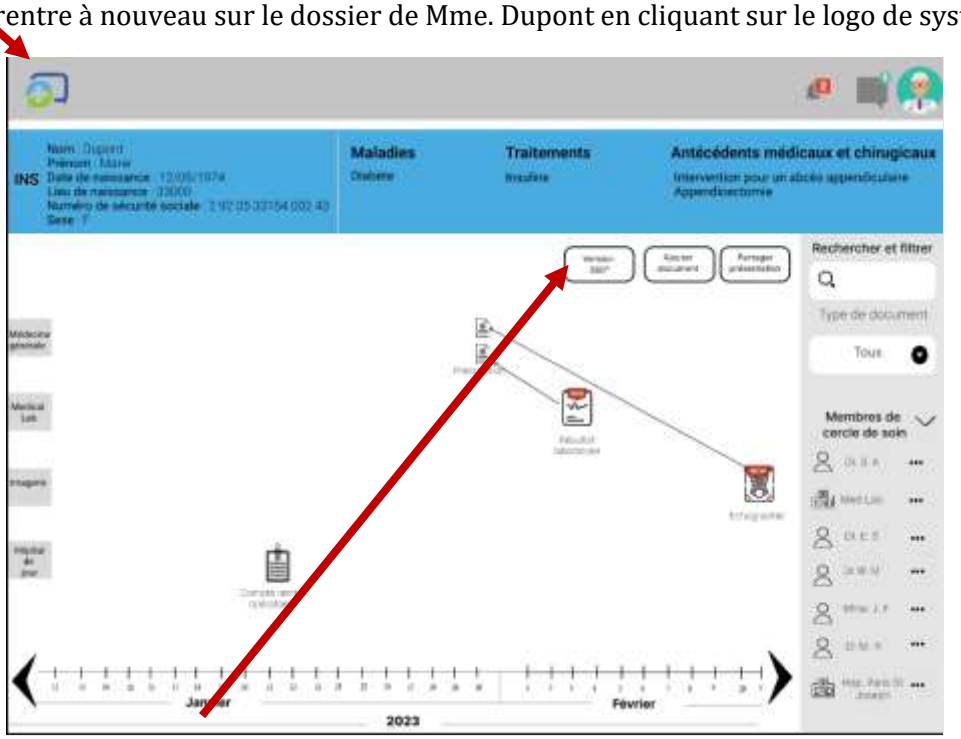
3. Il valide les informations sur le document



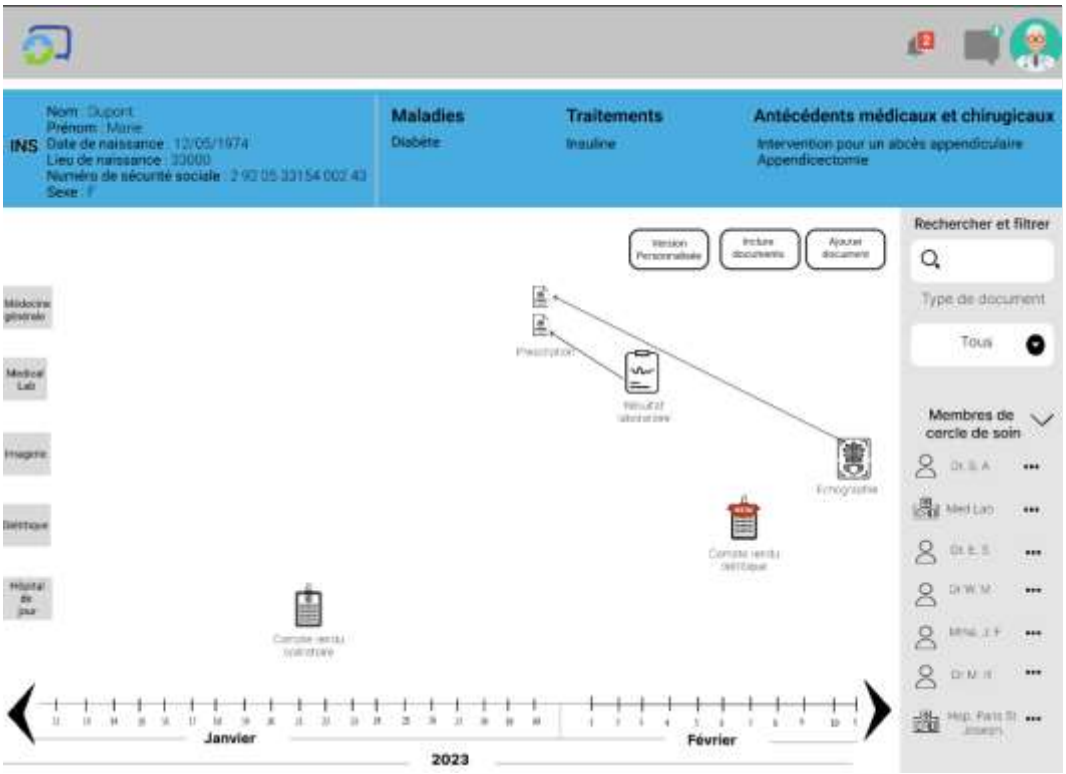
Scénario 2 : consultation de contrôle

a. Vérifier les documents générés depuis la dernière consultation

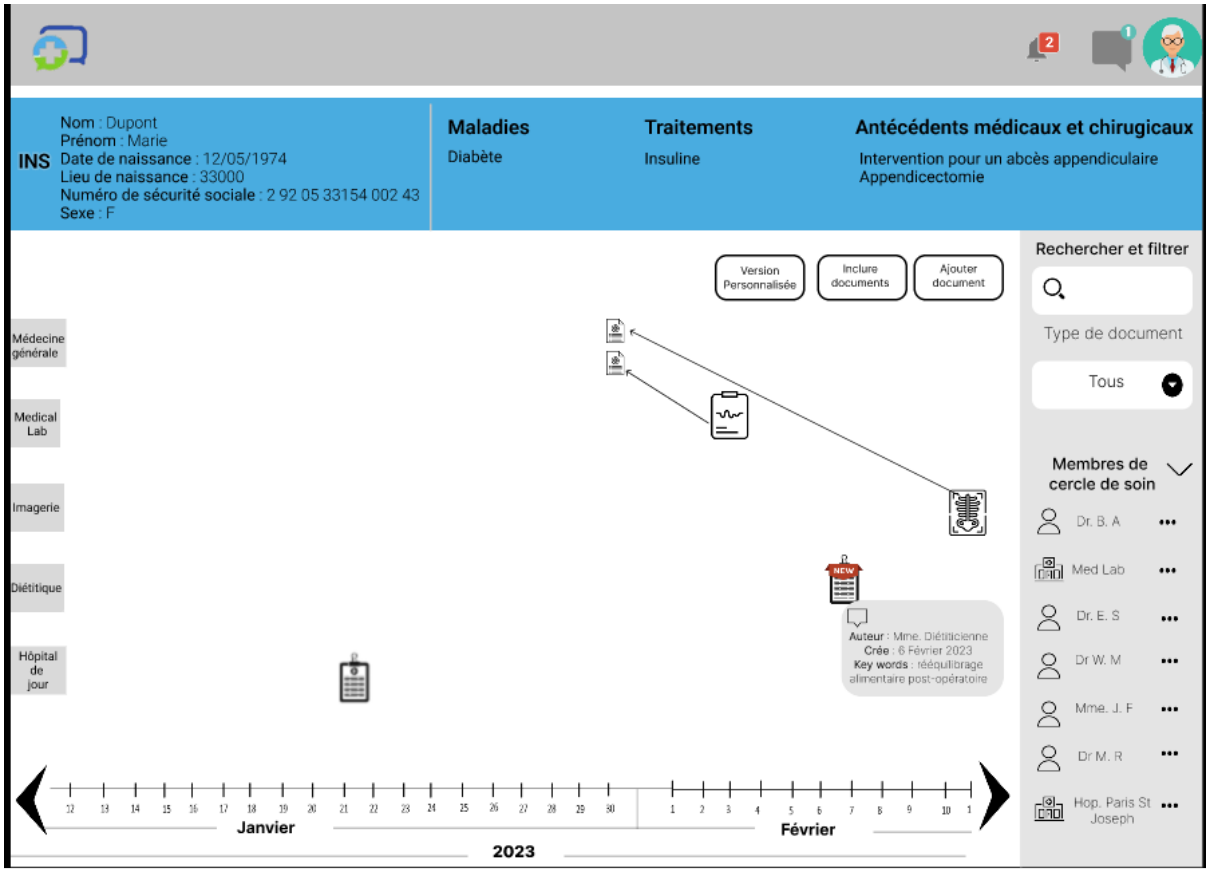
1. Il rentre à nouveau sur le dossier de Mme. Dupont en cliquant sur le logo de système



2. Il clique sur vision 360°

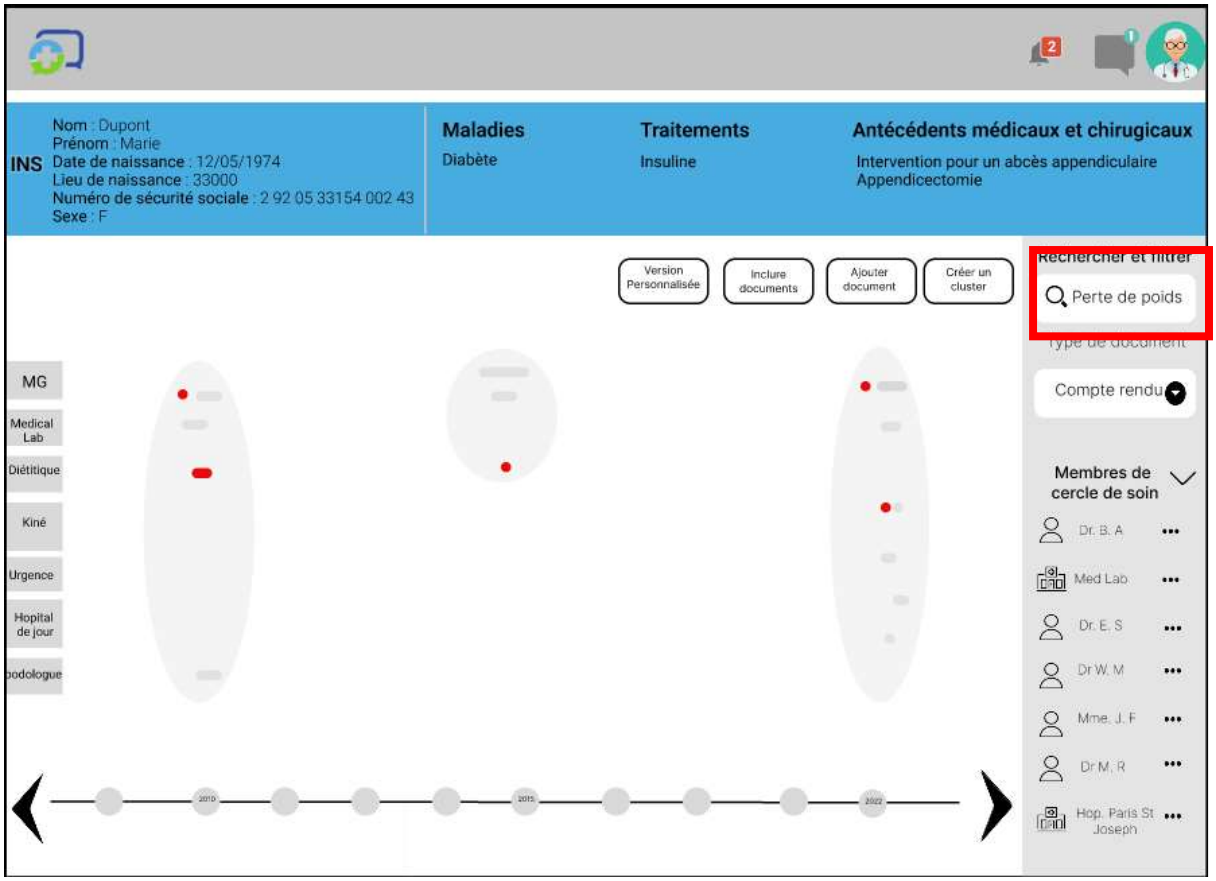


3. Il met la souris sur « compte rendu diététique »

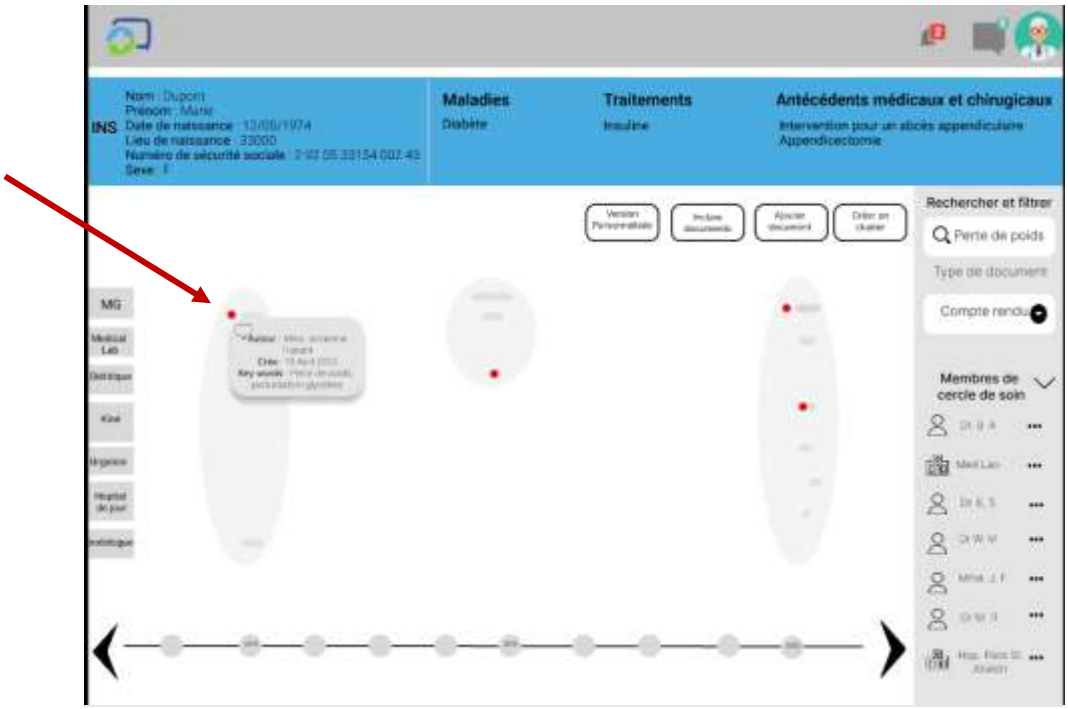


b. Apprendre plus sur un problème

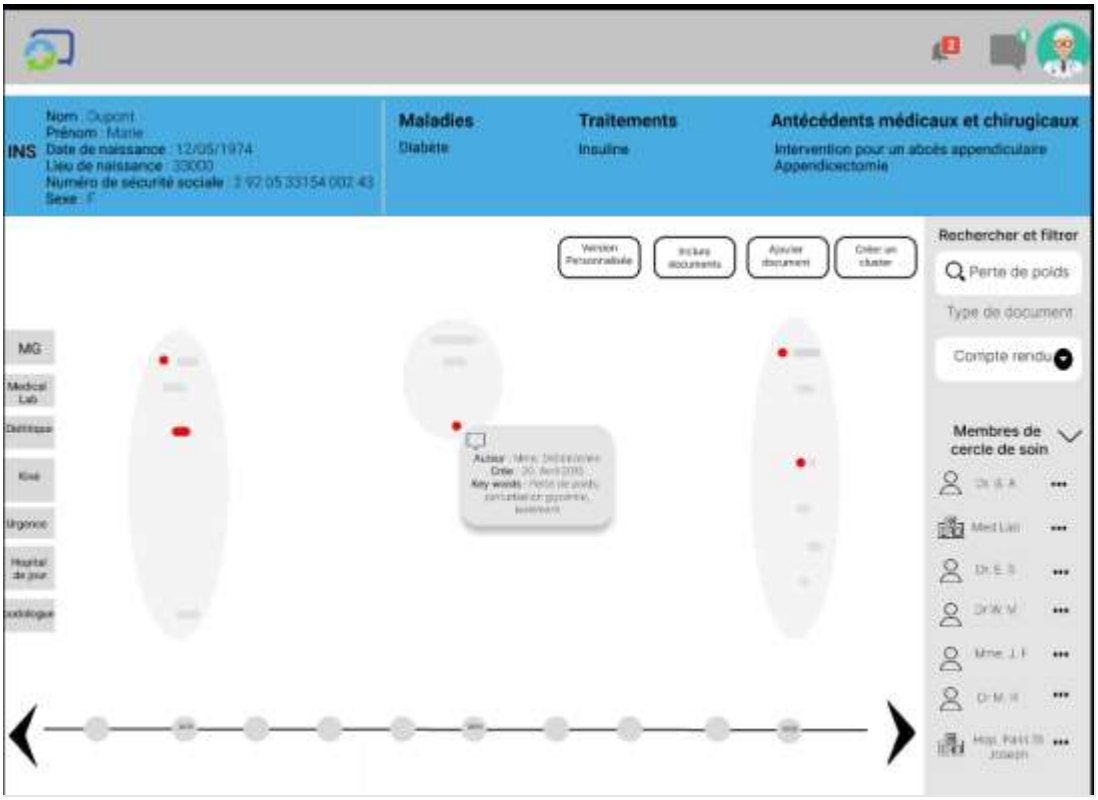
1. Il introduit une requête dans la zone de recherche et clique sur la zone



2. Il clique sur un document résultat de recherche

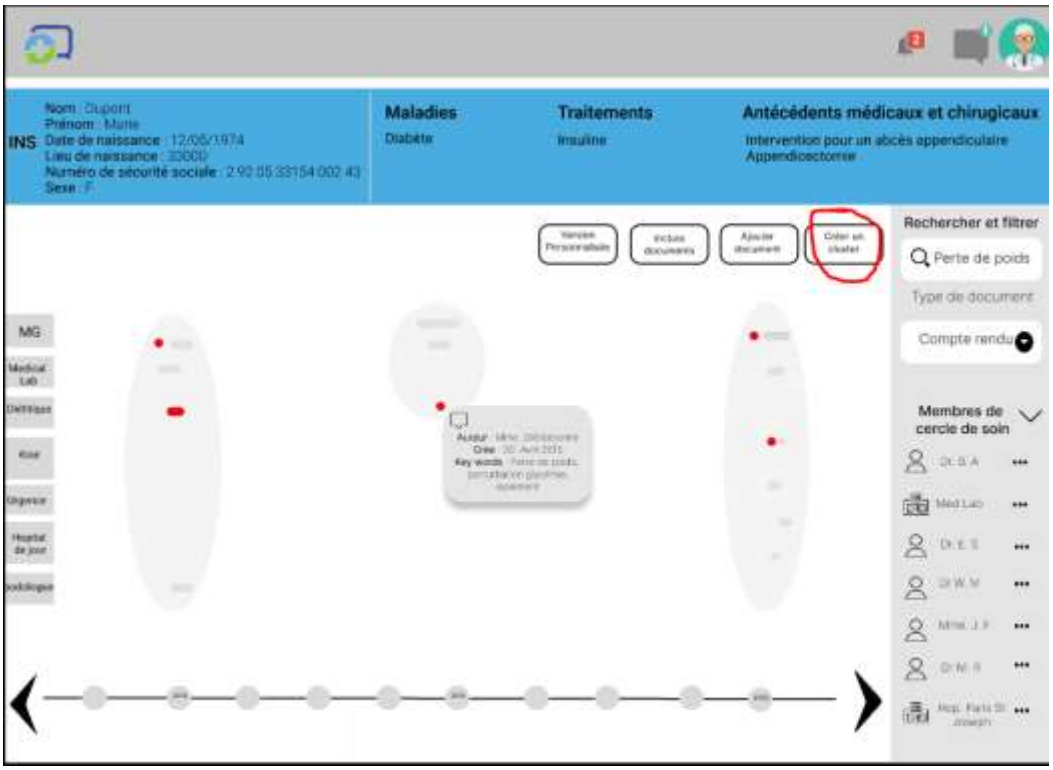


3. Il clique sur un autre document

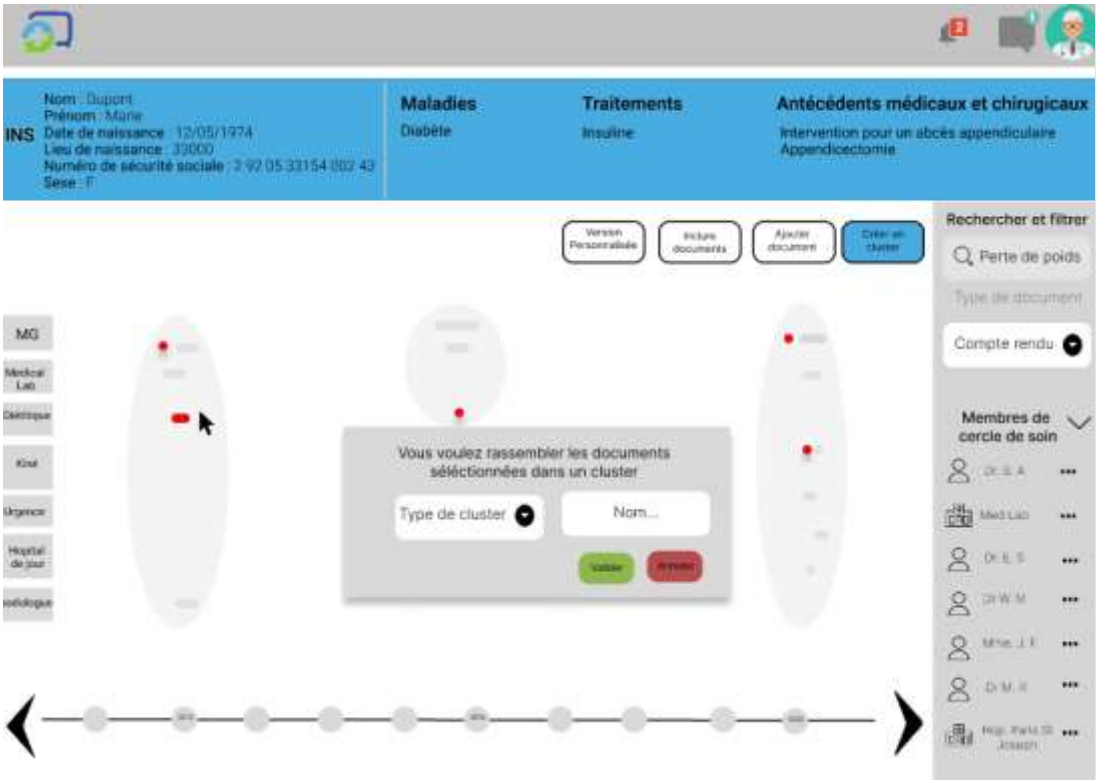

INS
Nom : Dupont
Prénom : Marie
Date de naissance : 12/05/1974
Lieu de naissance : 33000
Numéro de sécurité sociale : 2 92 05 33154 002 43
Sexe : F
Maladies
Diabète
Traitements
Insuline
Antécédents médicaux et chirurgicaux
Intervention pour un abcès appendiculaire
Appendicectomie
Rechercher et filtrer
Perte de poids
Type de document
Compte rendu
Membres de cercle de soin
MG
Urgence

c. Sauvegarder les documents concernant un problème

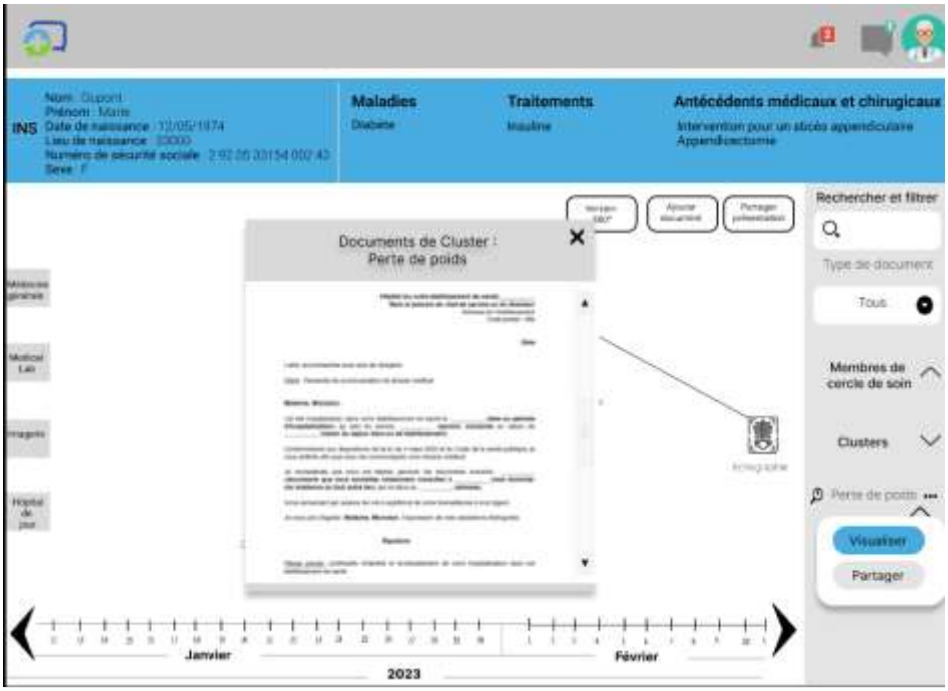
1. Il sélectionne des documents et clique sur « créer un cluster »



2. Il donne un nom au cluster et clique valider



3. Il clique sur les ●●● à côté du nom de cluster
4. Il clique sur visualiser

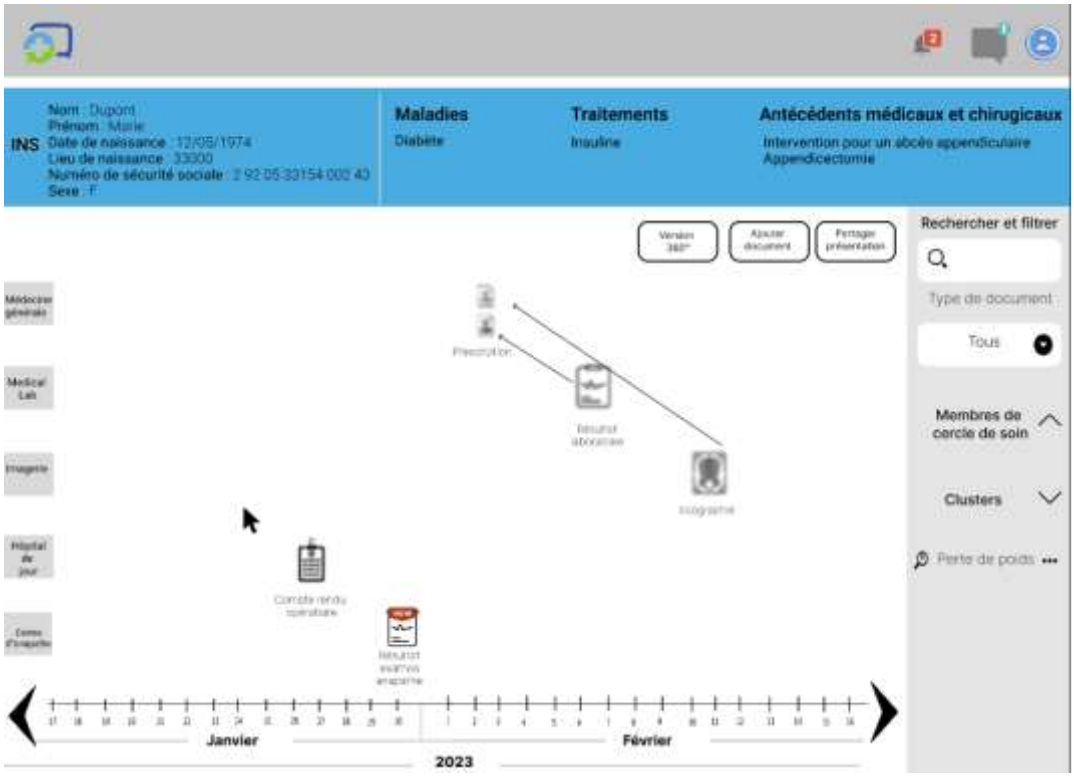


5. Il ferme le document en cliquant sur ✕

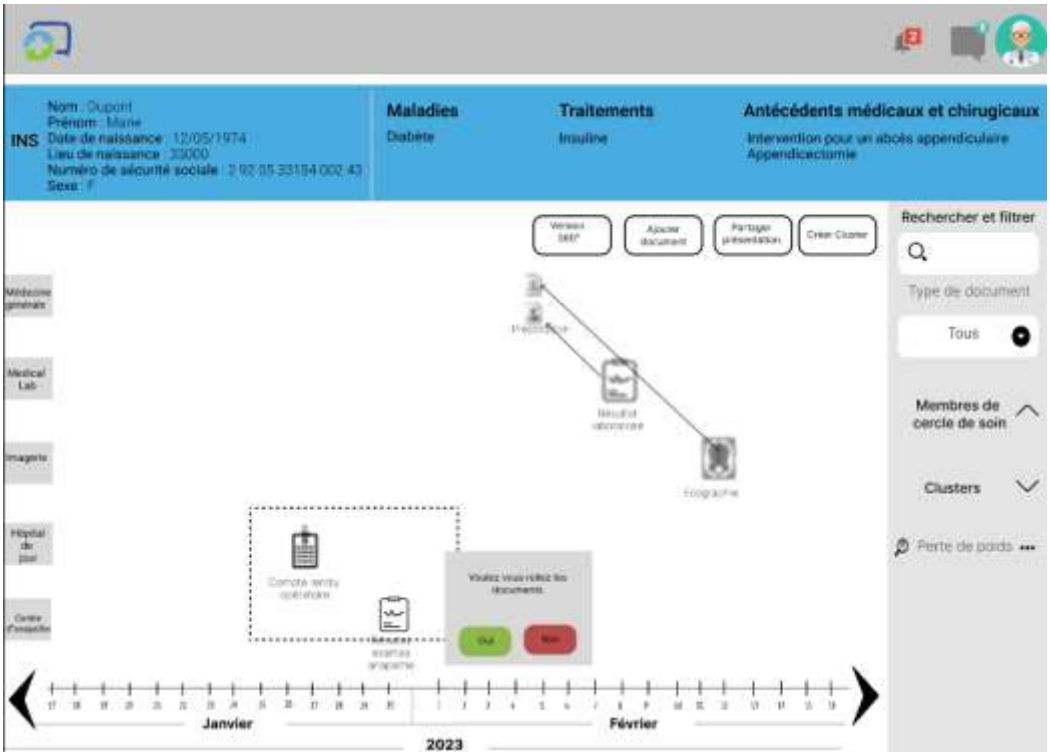
Scénario 3 : Travailler ensemble

a. Ajouter et relier des documents

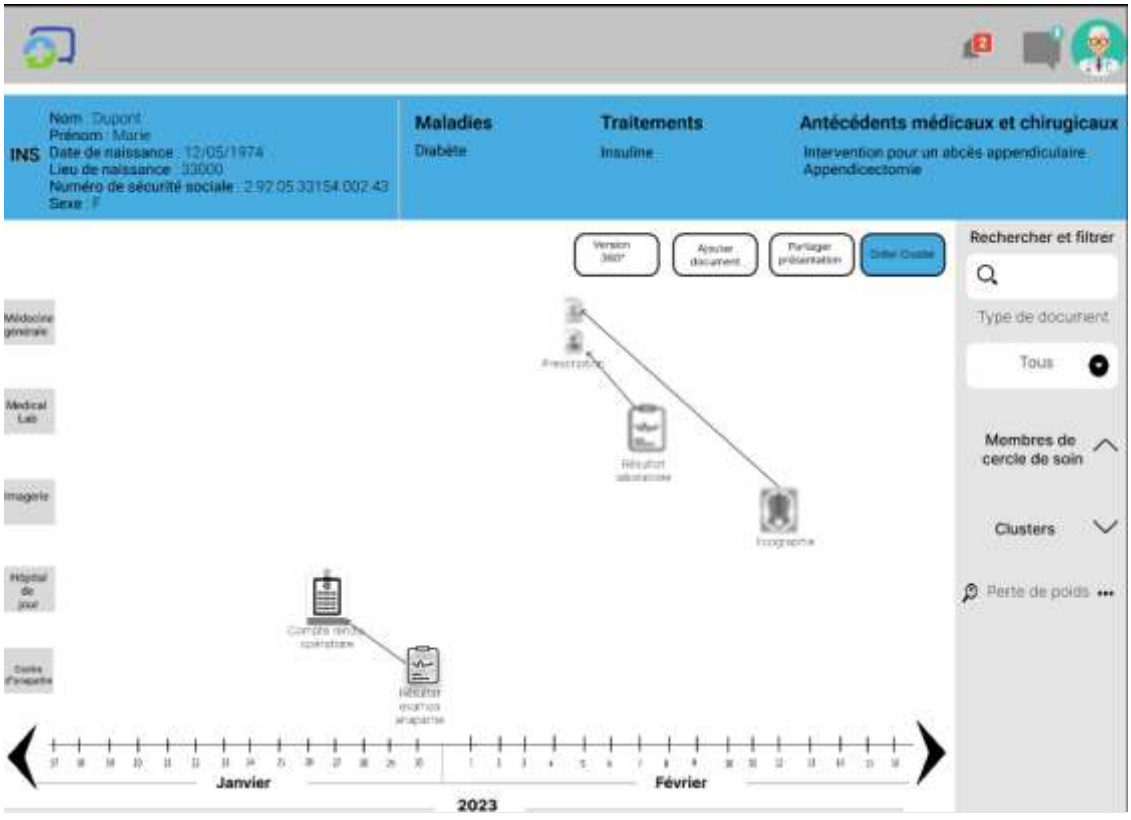
1. Il actualise le système en cliquant sur le logo
2. Il clique sur ajouter document
3. Il valide le choix



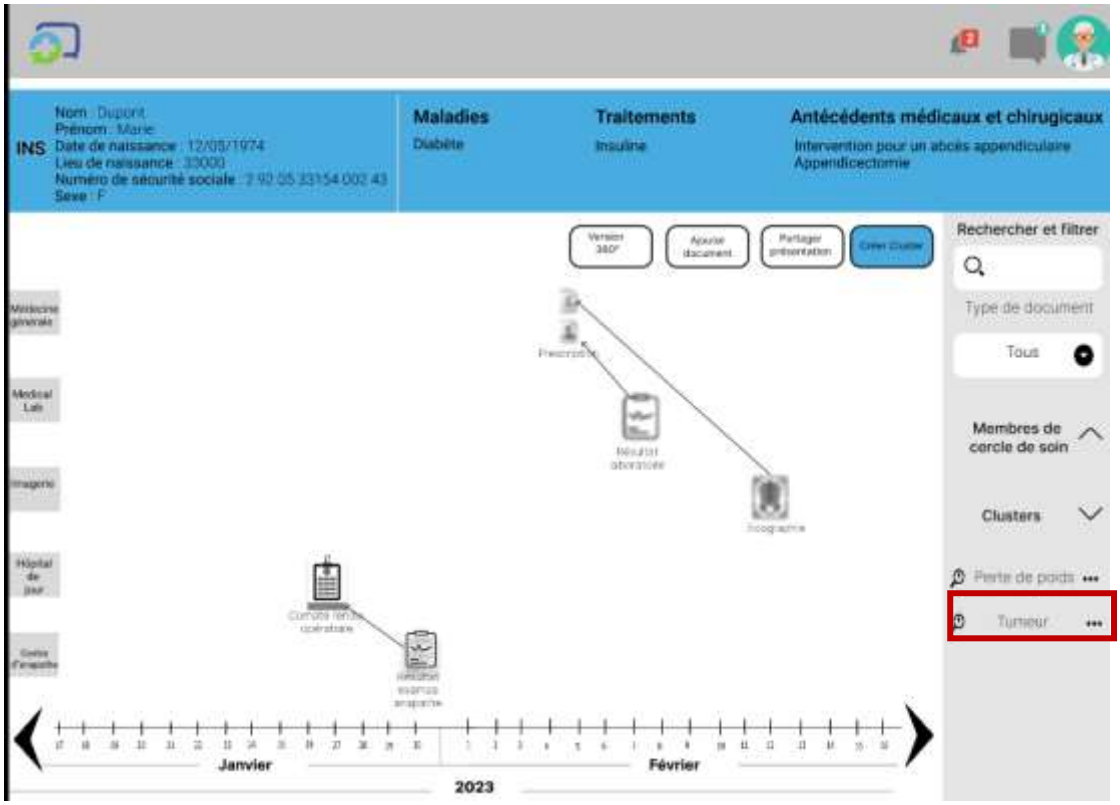
4. Il sélectionne les deux documents en cliquant sur et valide le choix



5. Il sélectionne les documents en cliquant sur « compte rendu »

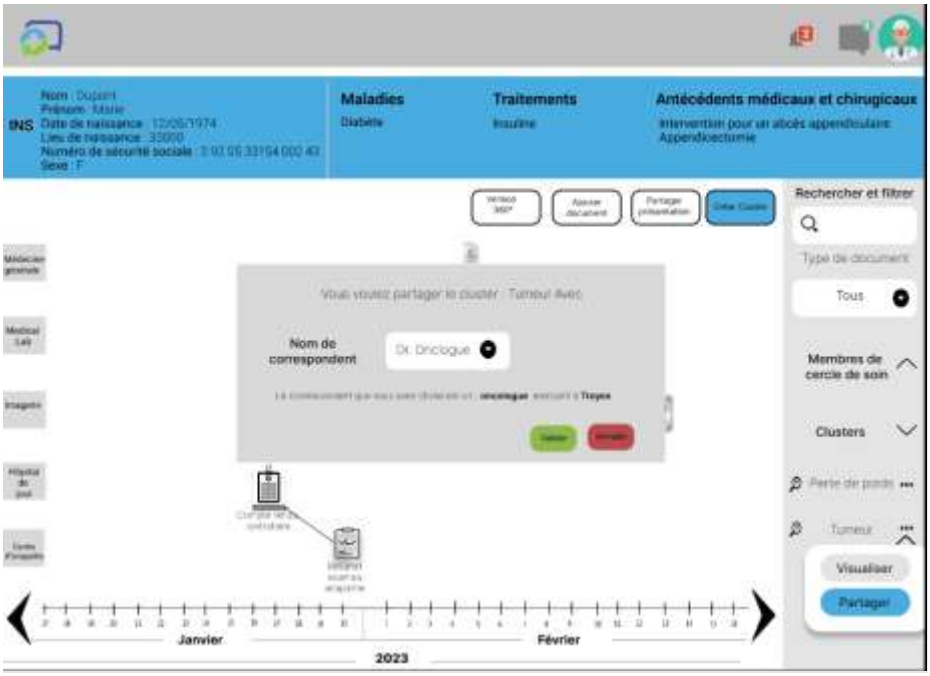


6. Il clique sur créer cluster



b. Partager cluster avec Dr. Oncologue

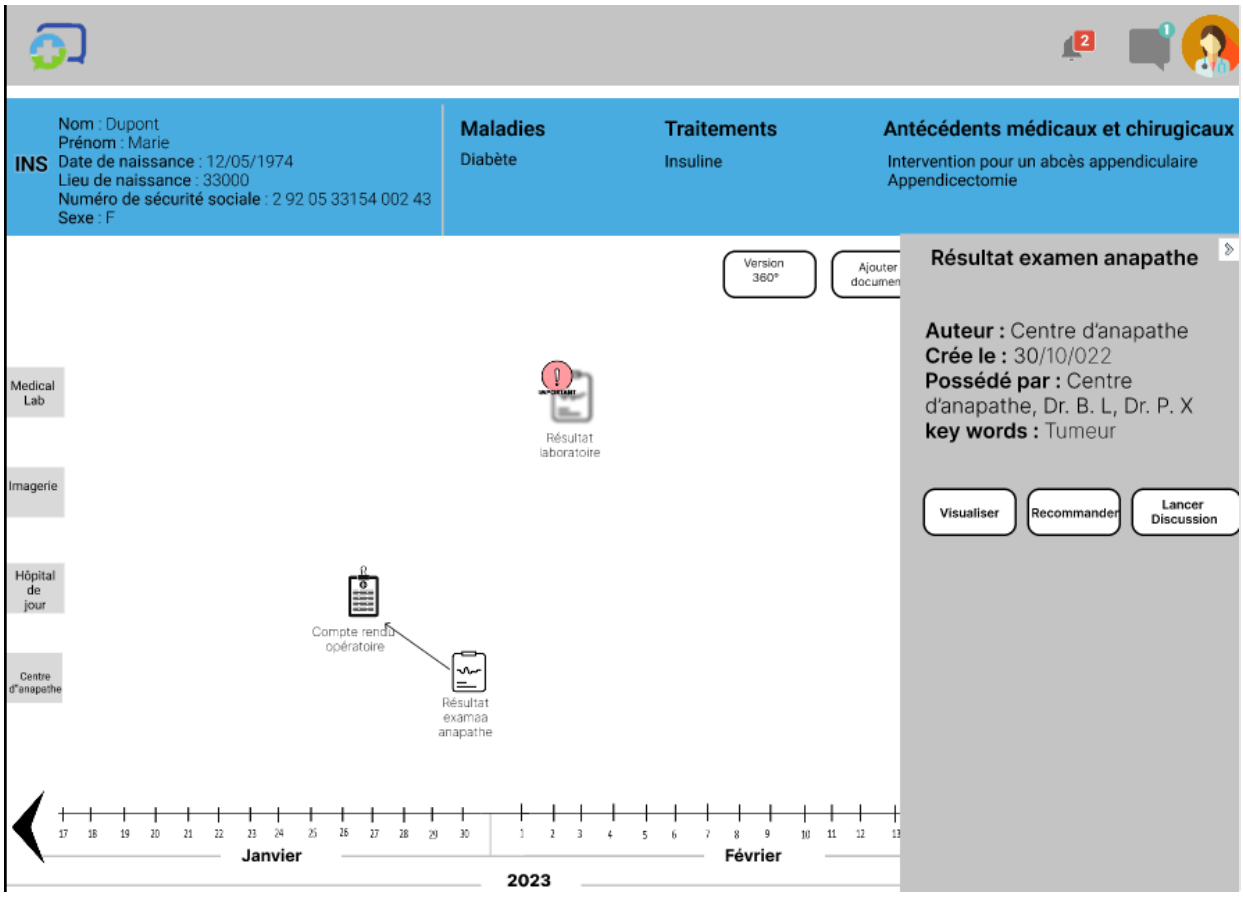
1. Il clique sur les ●●● à coté de nom de cluster « **tumeur** »
2. Il clique sur partager ensuite il introduit les informations du correspondant et valide



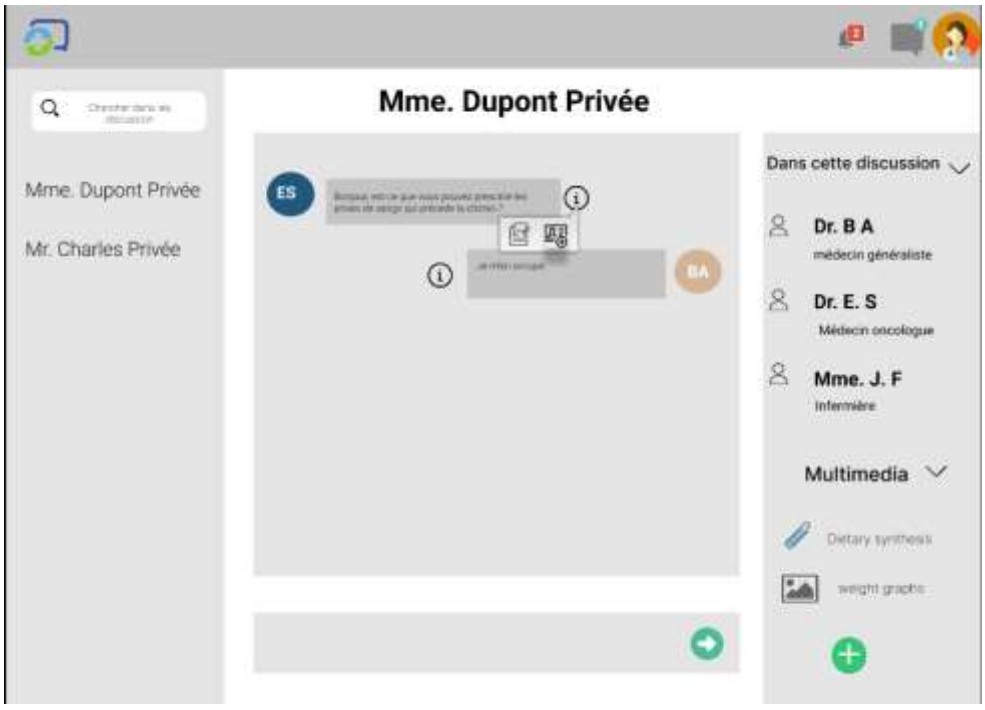
En validant, l'application nous renvoie vers la version personnalisée de Dr. Oncologue

c. Communiquer autour d'un document

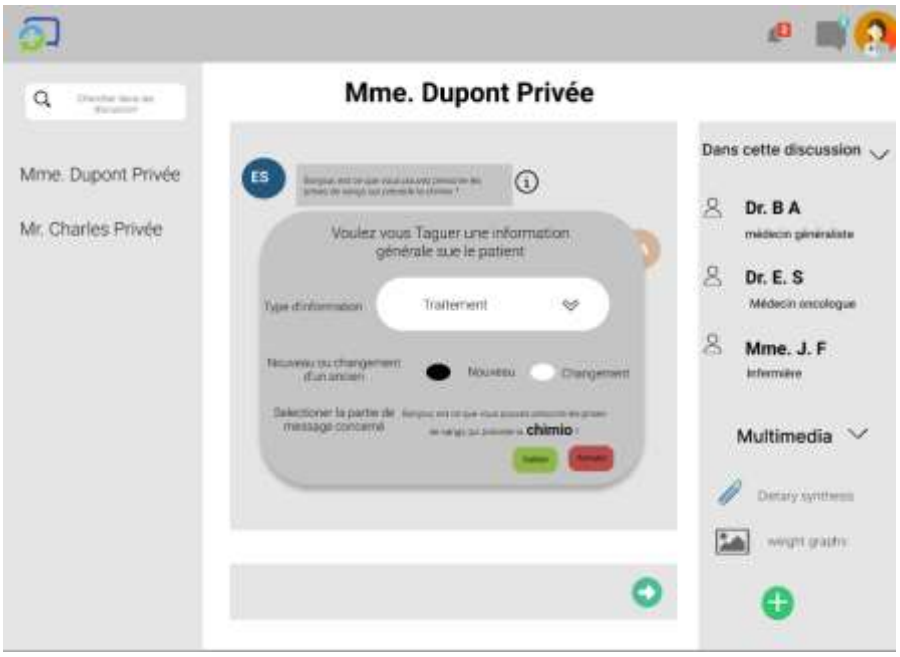
1. Dr. Oncologue clique sur document « Résultat examen anapathe »



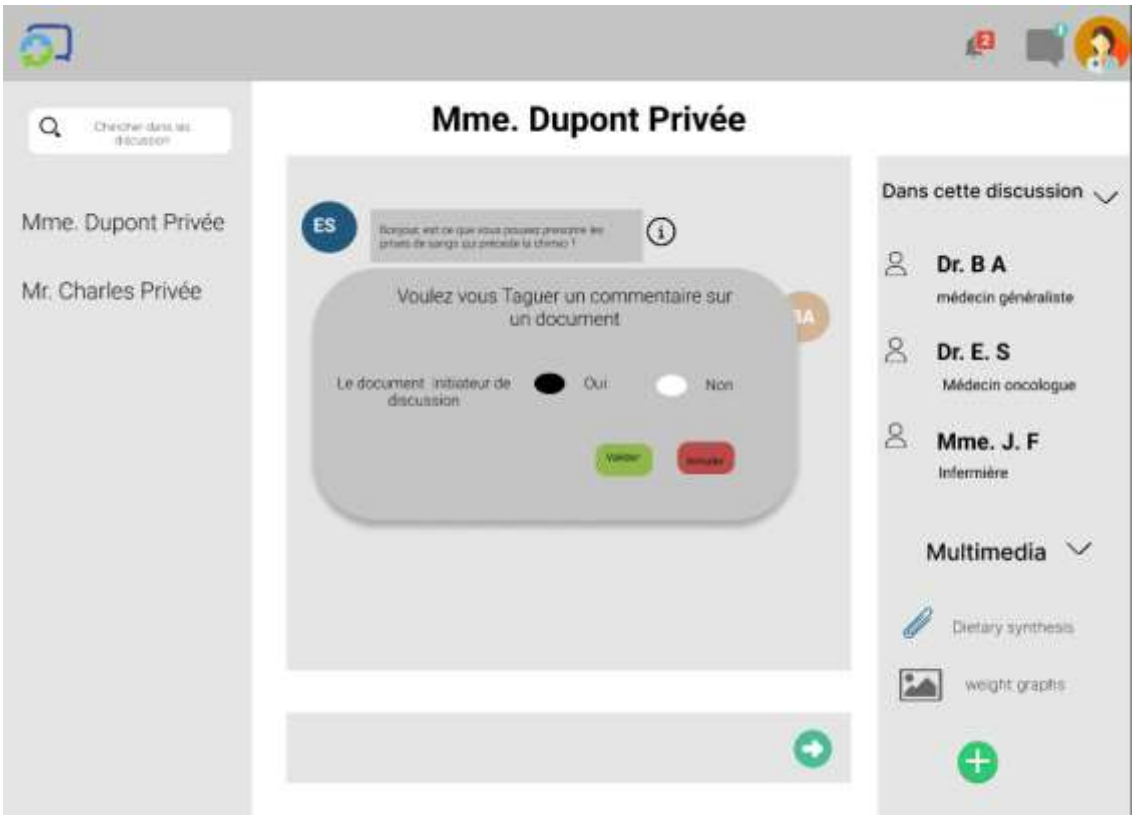
2. Il clique sur Lancer discussion

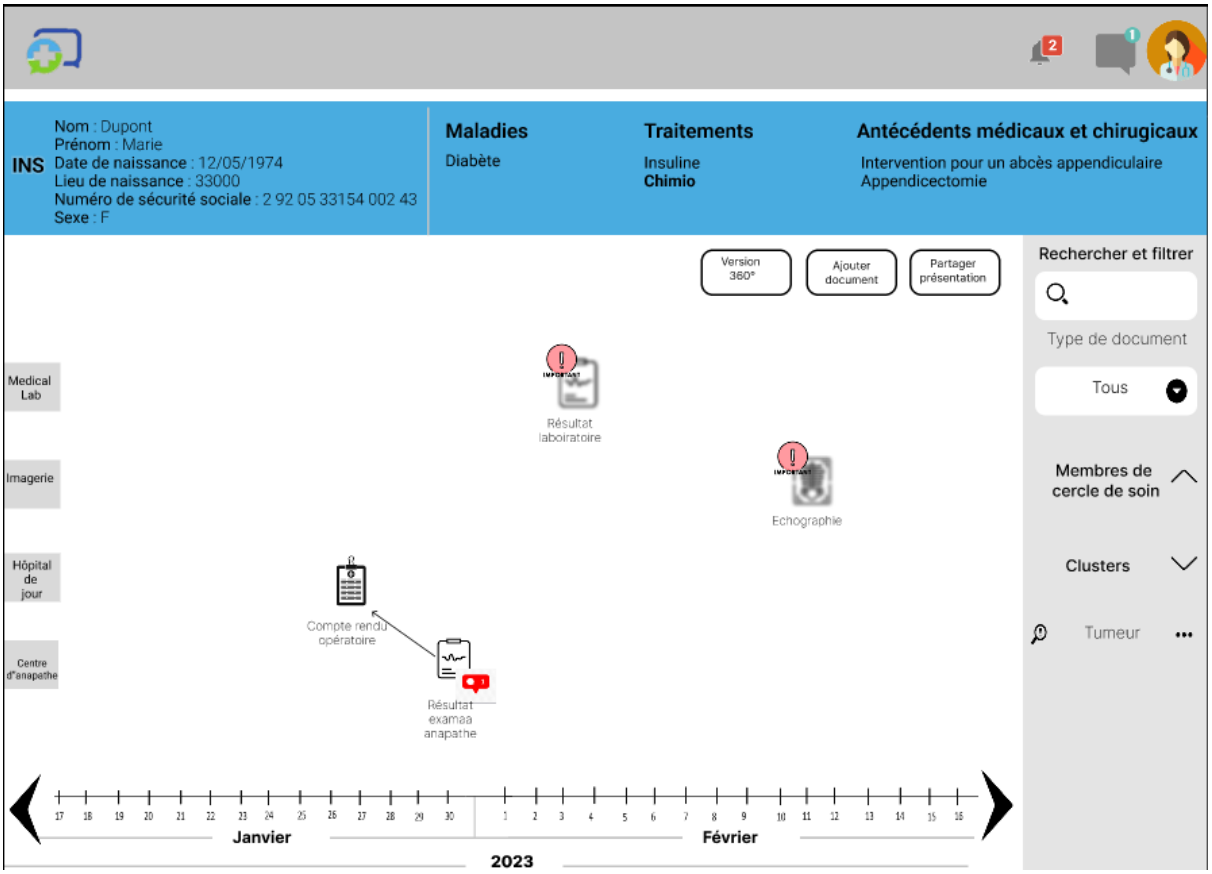


3. Il clique sur  pour ajouter information sur la patient
4. Il choisit les informations à ajouter en précisant leurs types et valide

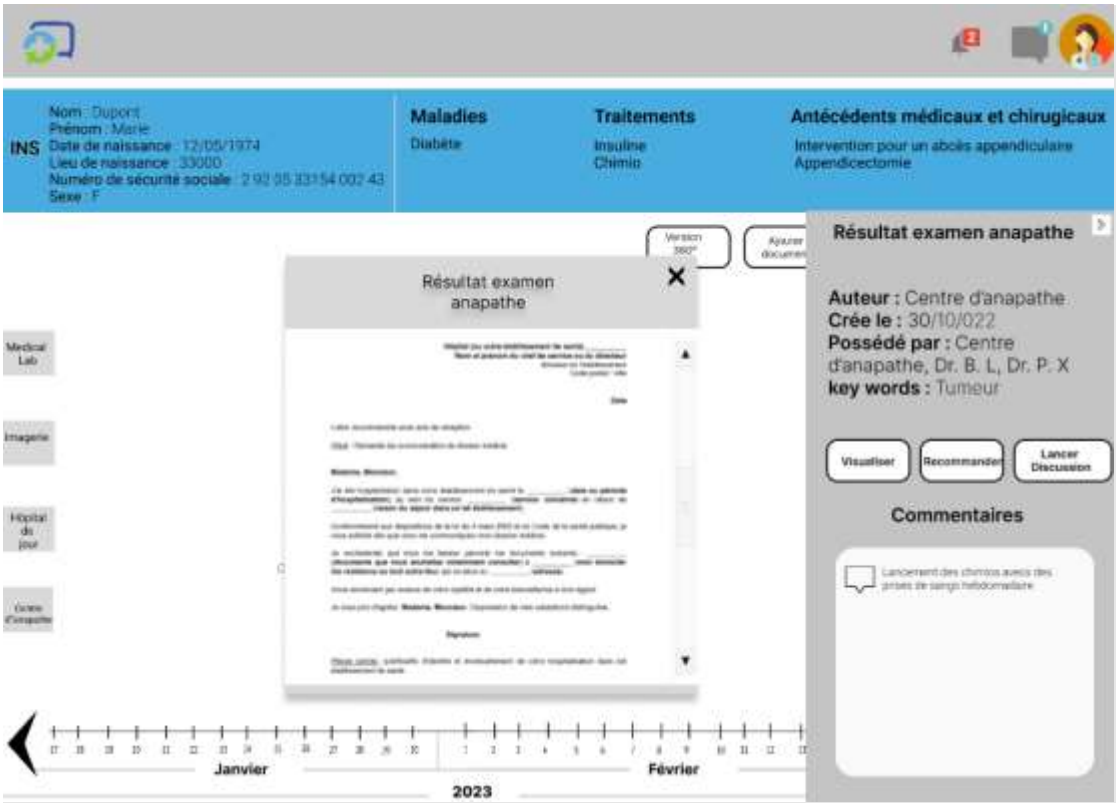


5. Il revient vers la discussion pour ajouter un commentaire sur le document : cliquer sur « résultat examen anapathe » -> lancer discussion -> ensuite cliquer sur 
6. Il valide le choix





7. Il clique sur le document ou le commentaire pour visualiser les commentaires et document



Annex 3 : Résumé de la thèse en Français

THESE

présentée par

Rahma MARREF

en vue de l'obtention du grade de

DOCTEUR
de l'UNIVERSITE DE TECHNOLOGIE DE TROYES

en SCIENCES POUR L'INGENIEUR

Spécialité : SYSTEMES SOCIOTECHNIQUE

Soutenir les parcours de soins par la visualisation des documents médicaux partagés et la communication

Soutenance devant le jury constitué des personnalités ci-dessous

JURY

Mme Sandra BRINGAY	PROFESSEURE DES UNIVERSITES	Rapporteure
M. Yannick PRIE	PROFESSEUR DES UNIVERSITES	Rapporteur
M. Gunnar ELLINGSEN	PROFESSOR	Examinateur
Mme Nada MATTA	PROFESSEUR UTT	Examinatrice
Mme Nathalie SOUF	MAITRE DE CONFERENCES	Examinatrice
Mme Khuloud ABOU AMSHA	MAITRE DE CONFERENCES	Dir. thèse
Mme Myriam LEWKOWICZ	PROFESSEUR DES UNIVERSITES	Dir. thèse

Abstract

Les études en Travail Coopératif Assisté par Ordinateur (TCAO) ont montré l'importance de l'awareness pour dans la coopération. Dans un contexte de coopération inter organisationnelle (IOC), la dispersion des données et des acteurs rend cette awareness difficile. Pour cela, nous avons adopté une approche centrée sur les pratiques pour comprendre comment une vue d'ensemble est construite par des acteurs divers, afin de proposer une solution informatique correspondant aux pratiques. Notre cas d'étude est celui de la coopération entre acteurs de santé dans le contexte des parcours de soins coordonnés. Dans ce contexte, les acteurs de santé ont besoin de créer une vue d'ensemble du cas d'un patient pour être en mesure de le traiter. Notre analyse a montré que l'élaboration de cette vue d'ensemble est un processus dynamique et personnalisé qui se base à la fois sur des documents et des interactions. Sur la base de cette compréhension, nous avons défini des principes de conception que nous avons traduits en un modèle appelé CaseOverview. L'évaluation de ce modèle nous a permis de valider nos propositions : un système pour la IOC doit permettre de passer d'une vue globale à une vue détaillée, d'offrir des vues basées sur les problèmes, et de favoriser l'awareness. Ce travail contribue à la fois aux travaux menés en TCAO et en informatique médicale, en adoptant une approche sur les pratiques qui nous amène à une proposition originale de solution pour l'élaboration de vue d'ensemble d'un patent, qui se focalise sur le rôle significatif des documents et des interactions.

Mots clés : Coopération inter-organisationnelle, visualisation, parcours de soins coordonnés, TCAO, Médecine -- informatique

Introduction

La coopération inter-organisationnelle est cruciale dans les environnements dynamiques tels que la santé, l'ingénierie et la gestion de crise (Menger et al., 2015; Mervyn et al., 2019). Cependant, plusieurs défis entravent l'action commune, notamment la dispersion géographique, la fragmentation de l'information et les différences d'objectifs, de rôles et de processus de travail de chaque organisation (Roy et al., 2017; Saoutal et al., 2015; Svensson, 2019). Pour résoudre ces problèmes, l'"awareness" est un élément fondamental qui permet aux groupes de gérer le processus de travail collaboratif (Schmidt, 2002). Afin d'établir cette "awareness" des actions menées, et des acteurs en charge, constituer une vue d'ensemble d'une situation apparaît comme une solution qui permet aux acteurs de percevoir les objectifs, les décisions passées et futures, et les acteurs participant (Hornbæk & Hertzum, 2011). Cette vue d'ensemble peut être établie grâce à des systèmes de visualisation (Hornbæk & Hertzum, 2011; Spence, 2007). L'obtention d'une vue d'ensemble est une activité dynamique qui change avec l'évolution de la situation et qui exige des interactions (Bjerknes & Kautz, 1991). Pour soutenir la création de cette vue d'ensemble à l'aide de solutions de visualisation, il est nécessaire de réfléchir à la manière de consolider les informations fragmentées dans un système de visualisation unique, et à la manière de présenter ces informations pour répondre aux attentes de chaque acteur, en leur permettant de développer la vue d'ensemble dont ils ont besoin, et ainsi de favoriser leur coopération. Les recherches antérieures sur la conception d'interfaces ont mis en évidence la nécessité de prendre en compte la pratique professionnelle pour comprendre comment les vues d'ensemble sont construites et ainsi informer la conception de systèmes appropriables (Hornbæk & Hertzum, 2011). C'est cette approche de la conception basée sur les pratiques que nous avons adoptée, dans le contexte des parcours de soins.

Les programmes de soins intégrés (SI) visent à fournir des soins holistiques et intégratifs centrés sur le patient et répondant à ses objectifs de santé (Kodner & Spreeuwenberg, 2002). Cependant,

réunir les perspectives des différentes parties impliquées est un défi important (Tian et al., 2022). De plus, la répartition et la distance géographique entre les institutions et les acteurs de soins ajoutent une couche de complexité, ce qui entraîne une fragmentation de l'information médicale, et augmente les efforts nécessaires pour coordonner les activités médicales (Svensson, 2019). Par conséquent, des initiatives ont été lancées pour créer des dossiers médicaux électroniques (DME) normalisés et centralisés pour fournir un accès intégral aux données de patient (Cresswell et al., 2012). Cependant, la documentation des DME sert les activités administratives plutôt que médicales, et de nombreuses études critiquent leur approche basée sur l'archivage, ce qui les rend difficile à parcourir et à utiliser (Adamson et al., 2020; Amir et al., 2015; Shah & Khan, 2020; Zhang et al., 2017). Des systèmes de visualisation ont été proposés pour contrebalancer cela et faciliter la lecture et la navigation dans les différents contenus des DME afin d'obtenir une vue d'ensemble du cas d'un patient (Rind et al., 2013). Ces systèmes de visualisation se concentrent sur l'agrégation et l'affichage des données structurées sans tenir compte des pratiques de travail cliniques (Jensen & Bossen, 2016). Or les professionnels de la santé utilisent les données non structurées pour mieux documenter, comprendre, et suivre l'évolution de leurs patients (Sultanum et al., 2018; Winthereik & Bansler, 2007). Il est donc nécessaire d'adopter une approche centrée sur les pratiques pour comprendre comment les professionnels de santé réussissent à créer une vue d'ensemble des patients afin de concevoir des systèmes qui s'intègrent dans leurs pratiques.

Nous avons donc étudié les pratiques des acteurs de soins intégrés, et avons identifié comment ils élaborent et utilisent une vue d'ensemble pour assurer la continuité et la cohérence des soins. Pour atteindre ces objectifs, nous avons mené une étude de cas en utilisant des méthodes de recherche qualitatives. Nous avons interrogé des acteurs de soins issus de pratiques et de secteurs variés entre janvier et octobre 2021. Cette étude qualitative s'est déroulée en trois étapes.

1) Une étude empirique des pratiques coopératives permettant aux acteurs du soin de construire une vue d'ensemble. L'analyse des données recueillies au cours de cette étape a révélé le rôle central des documents médicaux partagés en tant qu'éléments constitutifs de la vue d'ensemble du cas et le rôle essentiel des interactions pour contextualiser et améliorer la compréhension du contenu partagé dans les documents. Notre 'analyse a également mis en évidence les difficultés d'identification des autres acteurs travaillant autour des patients, et les problèmes rencontrés au cours de l'échange et de la réception des documents médicaux.

2) La définition des principes de conception que nous avons traduits dans le modèle CaseOverview.

3) Une évaluation par le biais d'un atelier basé sur maquettes et des scénarios mettant en jeu CaseOverview, suivi d'une série d'entretiens.

Le résultat de notre travail de recherche contribue aux discussion en cours sur la manière d'améliorer la coopération inter-organisationnelle en soutenant la création d'une vue d'ensemble d'une situation. Cette vue d'ensemble permet l'awareness de la situation et des autres, ce qui facilite la coopération. Notre travail contribue également au domaine de l'informatique médicale en proposant un nouveau système de visualisation et de navigation de l'information médicale qui promeut promouvoir la coopération dans le contexte des soins intégrés.

Revue de la littérature

2.1 Les défis de la coopération dans les situations inter organisationnelles

La coopération inter organisationnelle (CIO) fait référence à une relation négociée dans le cadre d'un processus de communication continu et qui ne repose ni sur le marché ni sur des mécanismes de contrôle hiérarchique (Hardy et al., 2003). L'objectif premier de la CIO est de relever des défis importants qu'une organisation isolée ne peut pas gérer seule (Trist, 1983). Cependant, plusieurs défis entravent le succès de la CIO, notamment les défis liés aux ressources (Karam et al., 2018; van der Linden et al., 2009), à l'organisation (Hocevar et al., 2011; Saoutal et al., 2015; Stoll et al., 2010; Svensson, 2019) et à la gestion de l'information (Bossen & Grönvall, 2015; Stoll et al., 2010; Svensson, 2019). Pour surmonter ces défis, de nombreuses approches ont été proposées, telles que la définition d'objectifs communs, la mise en œuvre de procédures de travail normalisées, et la promotion de canaux de communication efficaces (Bossen & Grönvall, 2015; van der Linden et al., 2009). En outre, l'awareness joue un rôle important dans la CIO et les efforts devraient être orientés vers sa facilitation afin d'articuler les diverses activités (Bossen & Grönvall, 2015; Stoll et al., 2010; Treurniet & Wolbers, 2021); il s'agit de faire en sorte que les différents acteurs soient au courant de leurs rôles, et de leurs tâches (Dourish & Bellotti, 1992). C'est pourquoi le travail coopératif assisté par ordinateur (TCAO) a accordé une attention particulière à la possibilité dans les solutions technologiques de rendre possible l'awareness (Schmidt, 2002). Dans le contexte de la CIO, des travaux ont été menés pour sur le rôle de l'élaboration de vues d'ensemble d'une activité pour favoriser cette awareness et surmonter la fragmentation et la prolifération des données (Bjerknes & Kautz, 1991; Hornbæk & Hertzum, 2011).

2.2 le concept de vue d'ensemble

Les organisations rencontrent souvent des difficultés à coordonner leurs activités en raison de la fragmentation et du manque d'intégration des données documentées dans différents formats et par le biais de divers artefacts partagés et personnels (Muller, 2008; Persson et al., 2016). Il peut en résulter une mauvaise prise de décision, des actions redondantes, et une allocation inadéquate des ressources (Persson et al., 2016; Sarshar et al., 2016; Treurniet & Wolbers, 2021). Une vue d'ensemble est alors nécessaire pour comprendre les activités menées et parvenir à une coordination efficace (Bardram & Houben, 2018; Gustavsson et al., 2022; Vos et al., 2020). La vue d'ensemble Une vue d'ensemble ne se résume pas à un accès à des bases de données ou à des espaces de données partagées qui rassemblent et fusionnent les données distribuées (Treurniet & Wolbers, 2021). Chaque acteur a besoin d'une vue d'ensemble différente, en fonction de sa situation (Bertelsen & Bødker, 2001). Il est donc impératif d'examiner les pratiques de travail, les objectifs et les méthodes divergentes mobilisées par les différents acteurs pour obtenir une vue d'ensemble, afin de faciliter le soutien technologique à l'élaboration de cette vue d'ensemble (Hornbæk & Hertzum, 2011).

2.3 Contexte de l'étude : Soins intégrés

2.3.1 La vue d'ensemble clinique

La création d'une vue d'ensemble clinique nécessite la collecte, la classification et l'analyse de données médicales (Bossen & Jensen, 2014). La quantité de données requise pour créer une vue d'ensemble complète est relative aux différentes contraintes auxquelles sont confrontés les acteurs des soins (Bossen & Jensen, 2014; Levy-Fix, 2020). Ces acteurs utilisent différents artefacts, à la fois physiques et numériques, et s'engagent dans des dialogues avec les patients, les proches et les autres acteurs de soins autour d'un patient afin de constituer leur vue d'ensemble

(Bardram & Houben, 2018; Bossen & Jensen, 2014; Hertzum & Simonsen, 2015). Deux types de données médicales sont mobilisées par ces acteurs : les données structurées et non structurées (Lovis et al., 2000). Les données non structurées, présentant la grande partie des données recueillies sur le patient, jouent un rôle important pour obtenir un aperçu des différents épisodes de soins (Mønsted, 2015; Sultanum et al., 2018). Elles jouent aussi un rôle important dans le travail coopératif en fournissant aux acteurs des soins un moyen pour échanger et partager les différentes données sur le cas d'un patient (Winthereik & Bansler, 2007). Pour faciliter l'obtention d'une vue d'ensemble, les DME normalisés ont été promus comme un moyen efficace de surmonter la fragmentation et de permettre un accès intégré aux données médicales dans le contexte des soins intégrés.

2.3.2 Technologies pour la création d'une vue d'ensemble

Les DME permettent de documenter, de stocker, d'accéder, et de partager les données des patients entre les différents prestataires de soins et institutions, ce qui a priori facilite l'intégration des activités et l'obtention des résultats souhaités en matière de soins intégrés (Kim et al., 2021). Toutefois, pour réaliser cette intégration, deux niveaux sont nécessaires : l'intégration des systèmes cloisonnés utilisés par les différents prestataires de soins et institutions, et l'intégration des données stockées dans ces systèmes.

2.3.2.1 Intégration des données

L'intégration des données médicales est essentielle à la réussite des programmes de soins intégrés, car elle permet de rassembler les données médicales dispersées d'un patient en un seul endroit, évitant ainsi la perte de données (Protti, 2009). L'intégration des données médicales permet aux prestataires de soins participant aux soins intégrés de suivre les différents types de données médicales qui étayent les divers processus décisionnels mis en place autour des soins centrés sur le patient. Elle encourage également la coopération entre les prestataires de soins, ce qui favorise la réussite globale des programmes de soins intégrés (Leventer-Roberts & Balicer, 2017; Protti, 2009).

Différents types d'intégration de données peuvent être utilisés en fonction de la qualité et de la capacité du système d'intégration, ainsi que des besoins en données des utilisateurs potentiels (Johnson et al., 2008). Six types d'intégration de données ont été identifiés par Leventer-Roberts et Balicer (2017) : l'intégration horizontale, verticale, historique, longitudinale, par indexation croisée, et les sources alternatives. Chaque type d'intégration comporte ses propres défis, et il peut être difficile d'identifier le bon type d'intégration pour chaque contexte. En outre, la nature des informations médicales, qui sont complexes, liées au contexte et ancrées dans les pratiques, fait de l'intégration des données une tâche difficile, en particulier lorsqu'elles traversent les frontières de différentes organisations (Protti, 2009).

2.3.2.2 interopérabilité des systèmes

L'intégration des DME est essentielle pour assurer la coordination et la cohérence des soins de santé. Cependant, l'intégration de divers DME est une tâche complexe, car chaque système fonctionne indépendamment pour répondre aux besoins des différents établissements de soins de santé. Trois approches ont été identifiées pour assurer l'interopérabilité technique et l'intégration des DME (Protti, 2009): l'intégration basée sur les messages, l'intégration virtuellement fédérée et l'intégration physique fédérée.

Malgré les efforts déployés pour promouvoir l'intégration des DME, différentes études ont montré que l'impact des systèmes sur les pratiques cliniques n'était pas évident. Des recherches dans le domaine du travail coopératif assisté par ordinateur ont mis en évidence le fait que ces

systèmes ignorent souvent les subtilités des pratiques de travail réelles, telles que la documentation et les commandes, ce qui conduit à des dossiers incomplets et obsolètes (Shah & Khan, 2020). De plus, ces systèmes stockent une grande quantité de données (Amir et al., 2015) organisées soit dans des répertoires (Hayrinen et al., 2008) où affichée dans des graphes qui ne sont pas adaptés aux pratiques des professionnels de santé (Corry et al., 2006) et qui rendent la création d'une vue d'ensemble difficile.

Cas d'étude

Dans ce chapitre, nous présentons le système de santé français, puis notre travail de terrain en précisant la méthode de collecte et d'analyse de données. Nous présentons ensuite nos résultats empiriques et nous discutons ces résultats afin de mettre en valeur nos contributions.

3.1 Contexte

L'état français a lancé en 2018 la "Stratégie Nationale de santé" (SNS 2022) dont le but est de moderniser le système de santé pour agir contre les inégalités (sociales et territoriales) d'accès aux soins, pour promouvoir les bonnes pratiques pour la prévention dans tous les axes de santé, et ainsi assurer une prise en charge des patients sécurisée, pertinente et de qualité . Afin de mettre en œuvre cette Stratégie Nationale de Santé, plusieurs mesures ont été mises en place notamment une Stratégie de Transformation du Système de Santé (STSS) rebaptisée MaSanté 2022, qui encourage la coopération entre les professionnels de santé en ville et à l'hôpital, les outils numériques et la mise en place de projets de santé dont le patient est le cœur, et la qualité de sa prise en charge la boussole dirigeant les actes des soignants .

Dans ces cadre, deux communautés professionnelles territoriales de santé (CPTS) et trois Équipes de soins primaires (ESP) qui rassemblent les professionnels de santé salariés et libéraux autour de projets de santé communs ont été créés dans le département de l'Aube. De plus, le département est un des cinq territoires pilotes qui participe à tester l'approche de responsabilité populationnelle qui définit des parcours de soin par populations souffrant d'une pathologie. Les pathologies prises en charge dans l'Aube sont le diabète et l'insuffisance cardiaque (Gomez et al., 2020). Afin de proposer un outil numérique commun à tous les acteurs de santé engagés dans cette démarche, le département participe au déploiement d'un outil e-parcours nommé Parcéo proposé par l'Agence Régionale de Santé ARS et le GRADs Pulsy. Cet outil permet d'échanger, de partager des documents patient, de disposer d'un agenda et d'un cahier de liaison, et de personnaliser le plan de santé de chaque patient suivi (Pulsy, 2022).

3.2 Méthode

3.2.1 Collecte de données

Nous avons mené une étude qualitative, en conduisant une série d'entretiens semi-structurés durant dix mois, de janvier à octobre 2021. Lors du recrutement des participants, nous nous sommes concentrés sur les acteurs de soins travaillant à la définition et au suivi des parcours de soins des patients diabétiques. Ainsi, nous avons contacté le Pôle Territorial de Santé Publique et de Performance des hôpitaux de Champagne Sud pour obtenir la liste des acteurs de santé ayant participé aux séances d'information sur Parcéo. Nous nous sommes également appuyés sur l'annuaire régional des professionnels de santé pour trouver d'autres acteurs traitant d'autres pathologies pouvant être liées au diabète. Nous avons envoyé plus d'une soixantaine de courriels, suivis par des appels téléphoniques pour donner plus de précisions sur les objectifs de notre étude.

Nous avons pu organiser 22 entretiens semi-structurés. Dix des personnes interrogées étaient employées par différentes institutions publiques, neuf avaient une pratique exclusivement libérale, et trois avaient une pratique hybride. L'expérience des personnes interrogées allait de 6 mois à 40 ans, et la durée moyenne des différents entretiens est de 45 minutes. Les entretiens se sont déroulés dans neuf lieux différents, répartis dans quatre villes du département de l'Aube. Tous les entretiens ont été enregistrés et retranscrits.

3.2.2 Analyse de données

Nous avons appliqué de manière itérative des techniques de codage ouvert (Corbin et Strauss 1990) en utilisant le logiciel Nvivo. Cela nous a permis d'identifier les thèmes liés aux stratégies de collecte et d'exploration des documents médicaux par les acteurs des soins. Au cours du premier cycle d'analyse, nous avons identifié des codes tels que "communication ponctuelle", "création d'une vue d'ensemble personnelle" et "partage opportuniste de documents". Dans l'étape suivante (codage axial), nous avons identifié la relation entre les différentes catégories de codes issues du codage ouvert. Cette analyse nous a permis de comprendre le déroulement de la coopération entre les acteurs de soins, et le rôle de la constitution d'une vue d'ensemble personnalisée, en soulignant les facteurs clés qui facilitent ou entravent cette création. Par exemple, nous avons identifié que la "création d'une vue d'ensemble personnelle" repose principalement sur le "partage opportuniste de documents" et nécessite dans de nombreux cas une "communication ponctuelle".

3.3 Résultats

3.3.1 Les freins à la coopération

Les parcours de soins intégrés visent à catégoriser les patients et à définir les soins nécessaires pour chaque catégorie, mais des difficultés entravent la coopération entre les acteurs des soins. Tout d'abord, le système de santé actuel ne permet pas d'identifier clairement les patients qui devraient entrer dans ces parcours. De plus, les patients doivent avoir un médecin traitant pour accéder aux programmes, ce qui exclut un certain pourcentage de la population. Il n'existe pas de méthode claire pour définir et coordonner les parcours de soins pour une catégorie de patients, ce qui conduit les acteurs des soins à travailler de manière isolée.

En effet, les acteurs des soins ont tendance à travailler en silo, les libéraux travaillent entre eux et les salariés des institutions entre eux, ce qui crée une concurrence et une compétition entre les différents secteurs, rendant difficile le partage des données et la communication entre les acteurs des soins qui sont censés coopérer. La fragmentation des données médicales due au cloisonnement et à la concurrence entre les différents acteurs de soins peut affecter les soins aux patients. Les patients peuvent ne pas informer leur équipe soignante de tous leurs épisodes de soins, ce qui cause des lacunes dans les traitements du patient ou des redondances dans les actions entreprises par les acteurs, et donc une augmentation des coûts des soins.

« On travaille seul, chacun dans son coin, d'une façon isolée. Ça, c'est le gros défaut de chacun d'entre nous. C'est un gros défaut pour la sécurité du patient. C'est un gros défaut parce qu'hospitaliser les patients, ça remplit les urgences et les urgences n'ont pas besoin de ça » Infermier_3

De plus, bien que le dossier médical partagé (DMP) ait été conçu pour éviter la fragmentation des données, les acteurs des soins ont exprimé des confusions quant à sa facilité d'utilisation. De plus, ils ont exprimé un besoin à définir de nouveaux rôles liés à la gestion des données. En même temps, ils ont expliqué que le DMP est trop complet et contient des données dont ils n'ont

nécessairement pas besoin. Par conséquent, ils sont submergés par cette grande quantité de données et ils se sentent perdus à chaque fois qu'ils cherchent une information dans ce dossier.

« Le problème est d'avoir un dossier médical qui ne soit pas mené par le patient et qui lui s'en chargerait de .... C'est-à-dire que le DMP a été lancé, mais le problème que ça prend de temps de remplir les données puis on n'a pas les outils pour les ouvrir quand il est en consultation. Donc il y a vraiment un problème pour récupérer toutes les informations pour faire une synthèse. C'est un des points de système actuel qui est vraiment défaillant donc ça entraine des examens redondants ça entraine … voilà … c'est dommage. » Endocrinologue_1

Dans ce contexte de fragmentation, les acteurs de santés optent pour les interactions généralement avec les acteurs qu'ils connaissent, dans les structures publiques ou privées, pour avoir accès aux données des patients. Cependant, cet accès n'est pas toujours garanti. En effet, pour respecter le secret médical, l'information des patients n'est pas systématiquement partagée entre acteurs, sauf s'il y a vraiment une raison qui justifie ce partage. Par exemple, les médecins des laboratoires n'ont pas le droit d'avoir des informations sur le diagnostic des patients et doivent négocier avec les médecins pour avoir ces informations quand c'est utile pour faciliter la lecture des résultats.

Pour résumer, malgré les efforts de l'Etat pour mettre en œuvre un système de santé intégré, les professionnels de santé travaillent toujours de manière isolée. Dans ces conditions, chaque professionnel de santé fait de son mieux pour obtenir une vue d'ensemble sur le cas d'un patient, ce qui lui permet de traiter et de suivre le patient. Pour atteindre cet objectif, ils utilisent les documents médicaux et interagissent quand il y a un besoin.

3.3.2 Pratiques existantes pour construire et utiliser une vue d'ensemble du cas du patient

Chaque acteur de santé a développé ses propres pratiques pour créer sa vue d'ensemble du cas d'un patient. De ces pratiques individuelles émergent trois points communs: 1) la collecte, la sélection et l'organisation des documents pour établir une vue d'ensemble sur le cas du patient ; 2) les interactions pour améliorer cette vue et 3) les stratégies pour utiliser cette vue d'ensemble pour prendre le patient en charge.

3.2.2.1 Collecte, sélection et organisation des documents

Créer une vue d'ensemble du patient est la première préoccupation des professionnels de santé dès leur première rencontre avec ce patient. Pour atteindre cet objectif, ils collectent, sélectionnent, sauvegardent et organisent les documents qu'ils reçoivent et qui donnent des informations sur les différents épisodes de la prise en charge de patients.

Ces documents comprennent en premier les lettres de références et les ordonnances, qui sont obligatoires pour prendre un rendez-vous chez un professionnel de santé. Ces documents détaillent en général la raison de l'envoi du patient et donnent quelques informations sur son historique médical. Cependant, il n'existe pas de consensus sur la manière de rédiger ces lettres. Par conséquent, certains acteurs joignent des résumés de contenu de leurs dossiers médicaux avec les lettres de références pour s'assurer qu'ils ont donné suffisamment d'information sur le patient. Cependant, fournir une grande quantité de données peut submerger les correspondants. Par conséquent, il arrive que toutes les informations ne soient pas lues, ce qui amène à des erreurs.

Certains professionnels de santé demandent aux patients d'amener leurs derniers résultats de laboratoire et les derniers comptes rendus des médecins spécialistes. D'autres comptent sur le patient pour qu'ils amènent des documents qu'il juge important. Ensuite, ils feuillettent ces

documents et décident de ceux qu'ils souhaitent conserver dans le dossier médical du patient qu'ils créent dans leurs logiciels métier.

« En fait, on a accès aux données et Crossway [logiciel métier c'est le dossier que Mme l'endocrinologue l'utilise, c'est le dossier que les médecins généralistes utilisent aussi ici à Saint Savine, parce puisqu'on veut aussi des patients de Saint Savine [ville à côté de Troyes]. Donc, on a vraiment accès aux données du patient et de tous les courriers, par exemple des courriers des médecins. Les résultats d'examens sont scannés aussi dans Crossway. On a vraiment accès à tout » Infermière_1.

Par la suite, si la prise en charge du patient demande davantage de détails, les professionnels demandent aux patients ou contactent leurs correspondants pour avoir les éléments nécessaires pour comprendre et clarifier les raisons des problèmes rencontrés.

Une fois que les professionnels de santé réussissent à poser un diagnostic, ils rédigent des comptes rendus, d'abord pour eux afin de mémoriser ce qu'ils ont vu et fait avec le patient. Puis, ils Ensuite, ils rédigent des comptes rendus résumés qu'ils envoient à leurs correspondants. Mais ces envois concernent essentiellement le médecin traitant qui a besoin d'être au courant de tout ce qui se passe autour de ses patients, les professionnels qui avaient envoyé le patient avec les lettres de références, et les professionnels qui traitent des pathologies qui peuvent être impactées par le nouveau diagnostic posé.

« Forcément il y a tous les correspondants qui sont les libéraux ou les hospitaliers donc chaque patient va avoir un médecin traitant et une multitude des spécialistes à qui nous devrons adresser, un pneumologue en ville, un pneumologue à l'hôpital, un cardiologue. Il y a une multitude de correspondants selon le cas de patient. » Endocrinologue_1

Pour conclure, la collecte et la sélection des documents partagés entre les professionnels de santé permet à chaque acteur de construire sa vue d'ensemble afin de traiter le patient. Cependant, les données mentionnées dans ces documents nécessitent quelques fois des compléments d'information. Dans ce cas-là, les professionnels interagissent pour contextualiser les informations et clarifier les ambiguïtés.

3.3.2.2 Communiquer pour améliorer la vue d'ensemble créée

La communication joue un rôle important dans le processus de construction d'une vue d'ensemble sur le cas de patient. Comme mentionné auparavant, les professionnels de santé peuvent demander les documents qui leur manquent pour améliorer leur compréhension de la situation. De plus, quand les professionnels de santé rencontrent des problèmes pour comprendre les éléments mentionnés dans les documents, ils échangent et demandent des explications.

« La communication elle est importante pour notre coopération parce que, par exemple, notamment entre psychologues et nutritionnistes, on va avoir des fois des du mal à recouper nos informations parce qu'on se rend compte que les patients par exemple lorsqu'ils veulent se faire opérer [chirurgie bariatrique]. Ils ont une idée bien précise en tête et ils savent ce qu'il ne faut pas dire. Sauf qu'il faut nous dire des choses. Ils vont me dire des choses à moi qu'ils ne diront pas au psy et inversement. Des fois, ça peut leur jouer les mauvais tours. D'ailleurs, parce qu'on recoupe les infos, mais ça ne colle pas, mais c'est très important. Donc la coordination, elle est là. En même temps, la communication directe entre les professionnels de santé est jugée par la méthode la plus adéquate pour alerter dans les cas des urgences et pour s'assurer que le message qu'on chercher à transmettre a été bien reçu par la bonne personne. » diététicienne_2

La communication joue donc un rôle très important dans le processus de construction d'une vue d'ensemble d'un cas patient, car elle permet à la fois d'avoir plus de détails, de vérifier et de consolider la compréhension, et de traiter des urgences.

3.2.2.3 Utilisation de la vue d'ensemble

Une fois la vue d'ensemble créée et maintenue via le dossier patient sauvegardé dans chaque logiciel métier utilisé par chaque professionnel de santé, cette vue d'ensemble est utilisée différemment selon la situation du patient.

a. Navigation chronologique

Les professionnels de santé feuillettent les documents sauvegardés dans un ordre chronologique décroissant. Donc, quand ils rencontrent les patients pour la première fois où pendant les consultations de suivi, ils commencent à lire les documents générés dernièrement avant de voir ailleurs.

« Les nouveaux patients viennent toujours avec d'énormes dossiers contenant de très nombreux documents. Certains médecins généralistes, avant leur retraite, impriment l'intégralité du dossier médical et remettent cette version imprimée au patient. D'autres stockent tout ce qu'ils ont sur une clé USB. Ensuite, lorsque nous recevons le patient, nous devons passer en revue tout ce qu'il a apporté pour continuer ses traitements. Cela prend beaucoup de temps, surtout pour les patients avec une comorbidité qui ont été suivis sur une longue période. Dans ce cas, nous avons examiné ce que les spécialistes ont écrit récemment. Cela nous permettra de mieux comprendre les différentes pathologies, traitements, chirurgies et toute information signalée par un drapeau rouge que nous devons prendre en compte. Ensuite, si nécessaire, nous vérifions à temps pour obtenir plus de détails. » Généraliste_2

b. Navigation basée sur les problèmes

Alors que la navigation chronologique permet aux professionnels de santé d'avoir une idée sur les derniers épisodes de prise en charge, quand ils rencontrent des problèmes ils cherchent à lire des documents qui décrivent des problèmes relatifs et similaires ou à lire des documents générés par des spécialistes qui traitement des problèmes similaires.

« Par exemple quand on va à domicile, et qu'on a un patient qui a du mal à respirer, si s'il a un dernier compte rendu de cardiologie qui dit au niveau cardiaque, ça va bien. Donc du coup si vous voulez, s'il n'est pas trop, s'il n'est pas trop conscient, on sait que du côté du cœur ce n'est peut-être pas ça. Il faut peut-être aller chercher ailleurs. » SOS_Médecin

c. Navigation basée sur les interactions

La communication joue aussi un rôle dans la navigation dans la vue d'ensemble. En effet, lors d'une interaction, un professionnel de santé peut recommander à un collègue de consulter un document qu'il n'avait pas considéré précédemment.

Par ailleurs, quand un professionnel de santé lit un certain document, il peut avoir besoin d'en lire un autre qui traite une autre étape du même épisode de soin. Par exemple, en lisant une prescription médicale, ils peuvent demander à lire les résultats de laboratoire qui ont menés aux prescriptions.

« Généralement, il est demandé au patient d'apporter tous ses documents antérieurs avant son hospitalisation. En fait, c'est ce que j'ai fait avec un patient la dernière fois. J'ai vérifié leur dossier médical. Cependant, après avoir discuté avec les stagiaires, ils ont souligné un document édité par

le service gynécologique qui détaillait un problème pouvant être lié au problème gastrique actuel. » Spécialiste

3.3.3 Freins dans construction de la vue d'ensemble des cas patients

Malgré les efforts menés pour construire une vue d'ensemble des cas patients, les professionnels de santé rencontrent des difficultés.

Premièrement, il n'est pas toujours facile d'identifier les autres professionnels de santé qui traitent le patient, surtout quand le patient n'est pas capable de donner les noms de ces personnes. Avoir leurs noms et adresses ne garantit toutefois pas la possibilité de les joindre. Dans le cas où ils cherchent à joindre des professionnels qui travaillent dans les institutions, ils doivent passer par le standard, de plus, quand la personne recherchée travaille aux urgences ou à l'hôpital de jour, sa disponibilité au moment de l'appel est peu probable. Quand ils cherchent à contacter des libéraux, ils tombent sur les secrétaires qui bloquent souvent les appels le temps passé à ces appels n'est pas rémunéré. De plus, les horaires des libéraux dépendent de leurs préférences personnelles.

Par ailleurs, l'envoi des lettres et comptes rendus n'est pas toujours aisé car chaque professionnel utilise des outils différents pour communiquer avec ses correspondant. Chaque professionnel cherche à rassembler l'ensemble des données et des informations collectées sur son propre outil.

« La difficulté, c'est de dire que la plus grosse difficulté aujourd'hui, c'est de connaître le moyen de réception de la personne à qui on veut écrire. Et ça, ça serait vraiment aussi un très gros progrès d'avoir un moyen simple. D'y parvenir sans passer son temps à trouver un moyen de le faire. Messagerie sécurisée, c'est bien. Il y en a plusieurs encore. On ne sait pas forcément lesquelles sont utilisées par leurs correspondants. Lesquelles sont opérationnelles et utilisées ? Ça m'est déjà arrivé d'avoir des médecins qui nous appelaient en disant que je n'ai pas reçu de courrier. Si on veut l'envoyer sur une messagerie, on aura comme réponse, je ne l'utilise pas, je ne le regarde pas. Donc on ne sait pas quoi utiliser réellement tellement il y a beaucoup des outils » Endocrinologue_2

Conception du modèle CaseOverview

4.1 Principes de conception

La construction d'une vue d'ensemble des cas patients est l'activité principale qui permet aux professionnels de santé de s'assurer de la continuité et de la cohérence de la prise en charge. Comme présenté dans nos résultats, section 3.3, les professionnels utilisent les documents partagés pour construire cette vue d'ensemble et mobilisent la communication pour la compléter. De plus, ils échangent ces documents via une multitude d'outils de communications. Ensuite, une fois qu'ils réussissent à rassembler les documents dont ils ont besoin, ils les sauvegardent dans leurs logiciels métiers pour maintenir cette vue d'ensemble.

Cependant, nos résultats ont montré aussi que les professionnels de santé rencontrent des problèmes pour construire cette vue d'ensemble, notamment pour identifier les acteurs autour d'un patient, et pour envoyer et recevoir les documents et les organiser pour les utiliser plus tard.

De plus, nous avons identifié les différentes stratégies pour feuilleter et utiliser la vue d'ensemble créée par chaque professionnel de santé.

En prenant en compte tous ces résultats, nous avons identifié des principes de conception pour la création d'un système permettant aux professionnels de santé de construire une vue d'ensemble des cas patients et de la visualiser. Nous organisons ces principes en deux catégories

: 1) les principes pour construire une vue d'ensemble globale, et 2) les principes pour construire une vue d'ensemble située, dépendant de chaque professionnel.

4.1.1 Les principes pour construire une vue d'ensemble globale

Le système doit permettre de :

a. Intégrer et s'aligner avec les outils de communication existants : il s'agit donc de créer une couche de visualisation qui s'intègre aux outils en place afin de permettre aux professionnels de santé de naviguer et d'explorer les différents documents collectés.

b. Collecter automatiquement les documents : pour les rassembler au même endroit.

c. Ajouter manuellement des documents : pour donner aux professionnels de santé la main pour ajouter les documents qui n'ont pas été échangés via les outils numériques.

d. Récupérer les métadonnées qui décrivent les documents : pour avoir une information sur l'auteur de chaque document, sa date de création, son moyen d'échange, et les mots clés qui décrivent son contenu.

4.1.2 Les principes pour construire une vue d'ensemble située

i. Adapter la vue d'ensemble à chaque professionnel : accéder aux documents qu'ils possèdent en premier.

ii. Permettre une awareness des activités et des acteurs : pour aider les professionnels de santé à suivre le développement des événements et à identifier les professionnels qui participent dans ces événements.

iii. Tracer la relation entre les documents : pour les aider à identifier les documents qui ont des relations sémantiques.

iv. Offrir des trajectoires de navigation basées sur le temps et le problème : pour leur permettre de voir les documents échangés récemment en premier et ensuite basculer vers une organisation orientée problème quand c'est nécessaire.

v. Soutenir une classification axée sur les problèmes : pour leur permettre de classifier les documents qu'ils feuillettent dans des catégories qui correspondent aux problèmes qu'ils traitent.

vi. Supporter une navigation basée sur l'interaction : pour tracer leurs précédentes navigations et proposer de nouvelles lectures.

vii. Offrir un espace d'échange : pour leur permettre d'échanger sur les documents partagés.

viii. Créer un profil utilisateur : qui apprend des interactions et préférences des utilisateurs pour améliorer leurs trajectoires de navigation

4.2 Solutions technologiques possibles

Pour traduire les principes des conceptions en un système réel, il faut prendre en considération les points suivants :

1**. Le stockage** : pour s'assurer de la disponibilité des documents sur la visualisation, il faut prévoir de stocker les documents à l'extérieur des serveurs mails. Pour cela, on donne aux professionnels de santé le choix entre les stocker dans des espaces personnels sur leurs ordinateurs ou les télécharger sur un serveur central. Cependant, cette deuxième proposition nécessite de respecter la règlementation concernant les données médicales.

2. **Extraction des documents** : Pour récupérer les documents des serveurs mails, on peut utiliser Python et les APIs proposés par ces fournisseurs de mails. Cependant, l'accès à ces documents dépend des politiques de confidentialité du service de messagerie, des conditions d'utilisation du fournisseur et du protocole utilisé par le serveur de messagerie.

3. **Extraction des métas donnée des documents** : Pour récupérer les données descriptives des documents, on peut utiliser les APIs des serveurs mails. Ensuite il faut les stocker dans une base de données pour les visualiser. Cependant, comme pour l'extraction des documents, on est contraints par les conditions posées par les serveurs mails.

4. **Extraction de contenu de documents** : On peut utiliser le TAL et l'analyse sémantique pour récupérer les concepts clés des différents documents. Cependant, d'autres documents peuvent être sur format image qui nécessite un traitement spécial pour récupérer leurs contenus. De plus, la qualité des données récupérées dépend de qualités de texte dans ces documents.

5. **Classification des documents** : pour déterminer le type de chaque document, on peut opter pour les algorithmes de classification tel que TF-IDF. Cependant, la précision de la classification dépend de la qualité des documents. Par conséquent, on propose de donner la main aux professionnels de santé pour valider les résultats de classification après chaque ajout de document.

6. **Présentation** : Prenant en considération la quantité des documents à visualiser qui peut augmenter de manière significative, nous proposons de déployer la visualisation sur une application web pour avoir un grand espace de navigation.

4.2 Présentation du modèle CaseOverview

L'interface du modèle comporte trois zones importantes (Figure 1). La zone en bleu, permet d'identifier le patient et les informations générales sur ses antécédents et les traitements qu'il prend. Le cadre à droite, permet d'effectuer des actions de filtrage et d'identifier les professionnels de santé qui participent dans le traitement de patient. La zone centrale est prévue pour permettre de visualiser les documents échangés autour de patient.

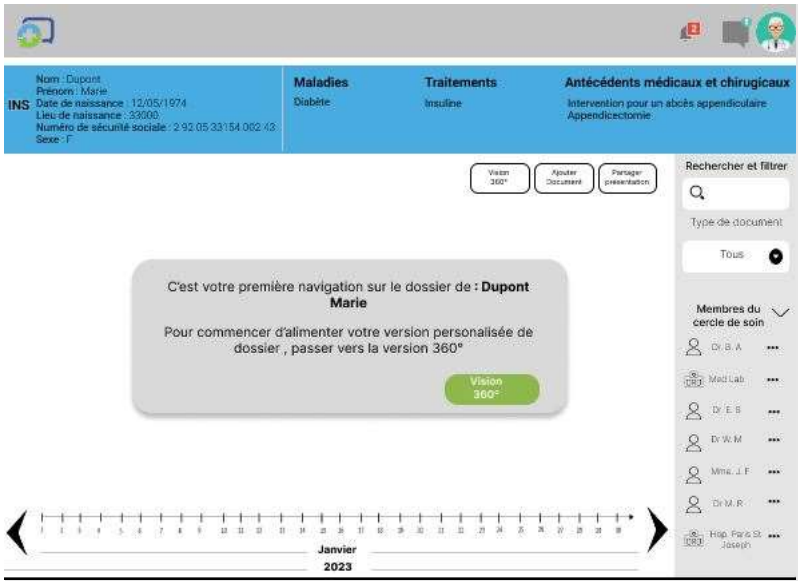


Figure 1: Fenêtre de la première connexion sur le profil de patient

Quand le professionnel de santé accède au profil de patient pour la première fois, sa visualisation est vide. Le système lui propose donc d'afficher la vue d'ensemble générale en cliquant sur «

version 360° ». Dans cette visualisation, il peut voir des nuages des documents alignés par mois ou années. Les documents sont présentés dans chaque nuage par des points de couleurs différentes. En passant la souris sur chaque nuage, le professionnel de santé peut visualiser les mots clés qui décrivent les documents appartenant à ce nuage (Figure 2).

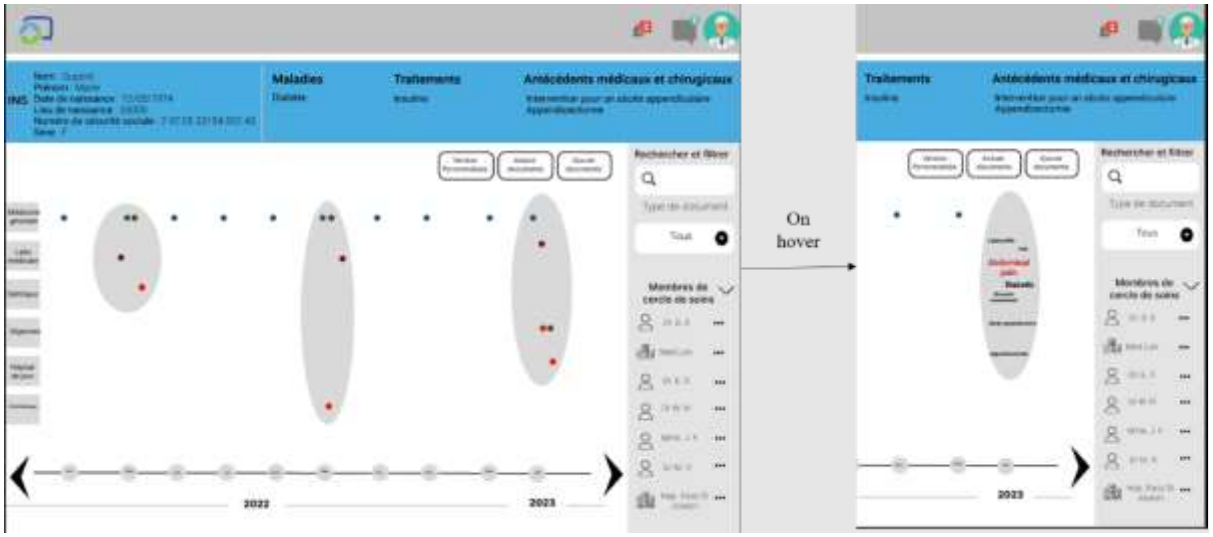


Figure 2: la vue d'ensemble globale qui s'étend sur plusieurs mois ou années

Ensuite, quand le professionnel de santé décide de focaliser sur un mois particulier, il clique sur ce mois et la visualisation s'ajuste pour donner plus de détails (Figure 3). Sur cette présentation, chaque document est présenté par une icône différente pour identifier son type et il est placé dans l'intersection entre sa date de création et le professionnel de santé qui l'a généré.

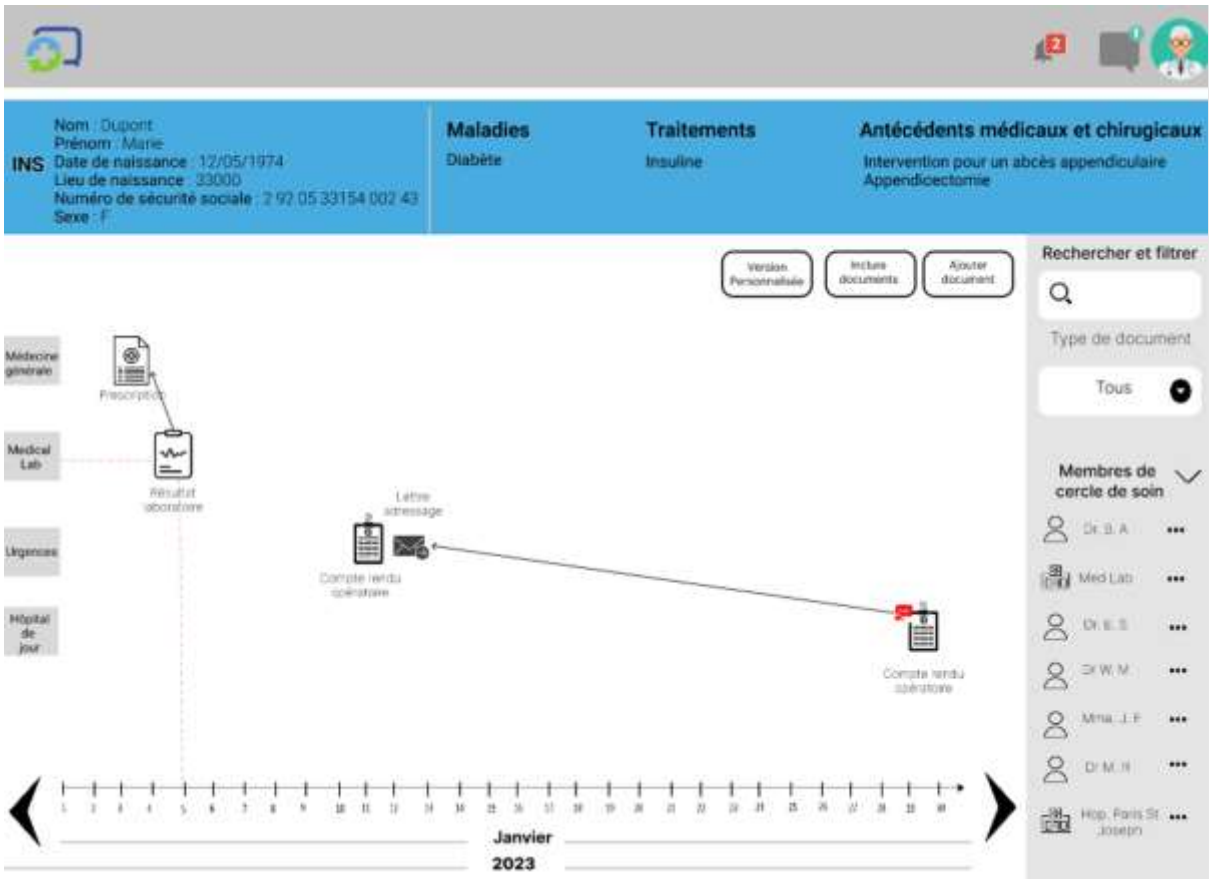


Figure 3 Vue focalisée sur un mois

Pour avoir plus de détails sur un document, il peut cliquer sur ce dernier, un panel s'affiche sur la gauche pour présenter plus de détails sur les métas donnés de documents avec des boutons pour le visualiser en entier (Figure 4). En visualisant un document, la version personnelle de professionnel de santé sur automatiquement ajustée pour inclure le document qu'il a ouvert. De plus, il peut sélectionner d'autres documents qu'il trouve pertinents pour les ajouter à sa version.

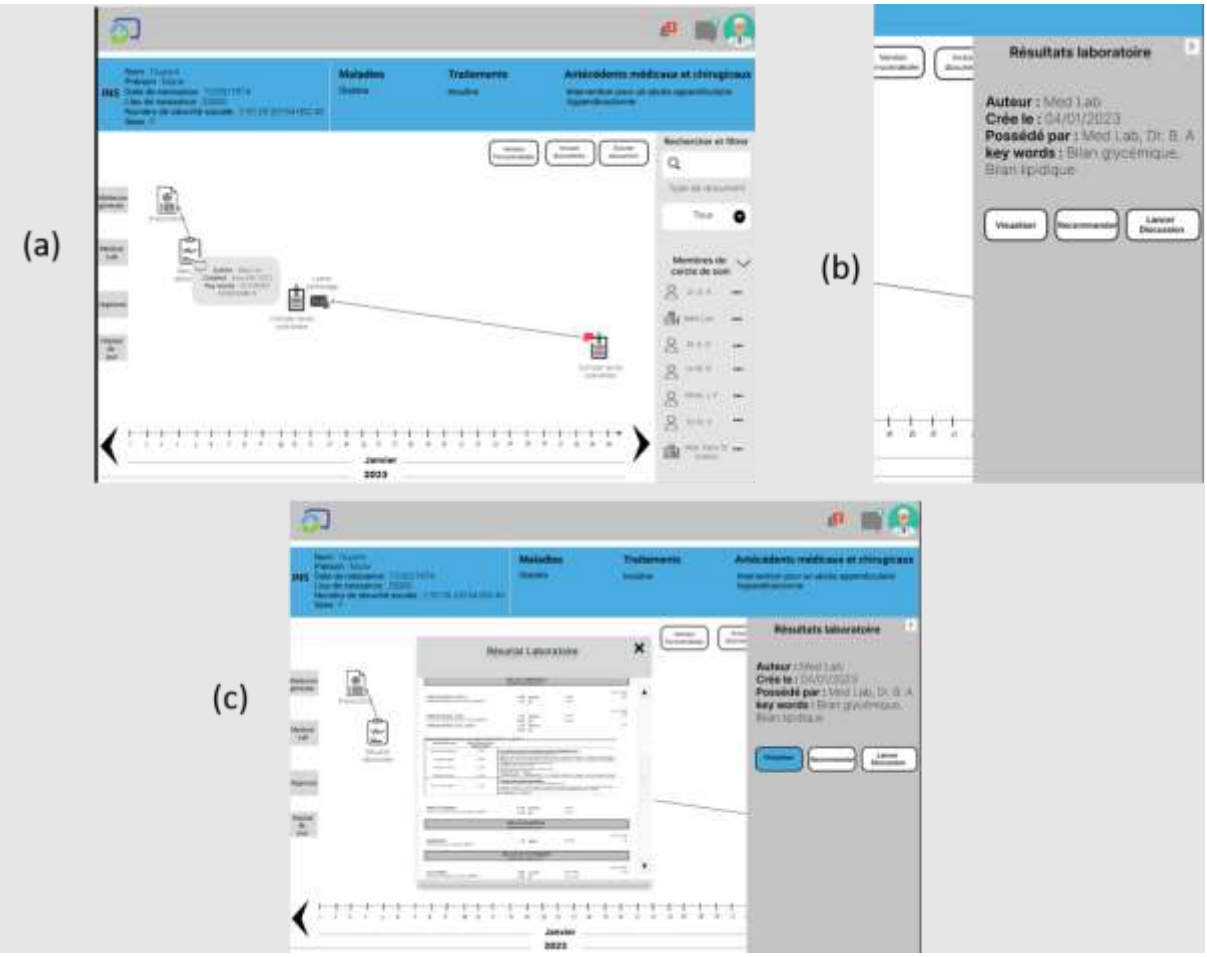


Figure 4 les trois niveaux de détails pour voir un document : a) en passant la souris, on voit quelques détails sur le document. b) en cliquant sur le document, on peut voir plus de mots clés et des métas donnés. c) en cliquant sur visualiser, on voit le document en entier.

Ensuite, à chaque fois le professionnel de santé reçoit un nouveau document sur l'un de ces outils de communication, il peut le trouver sur sa version personnelle de la vue d'ensemble avec un tag « new » (Figure 5). En même temps, si ces nouveaux documents sont des retours pour d'anciens documents, le système les relie pour permettre aux professionnels de santé de pointer leurs relations et de les feuilleter ensemble si nécessaire.

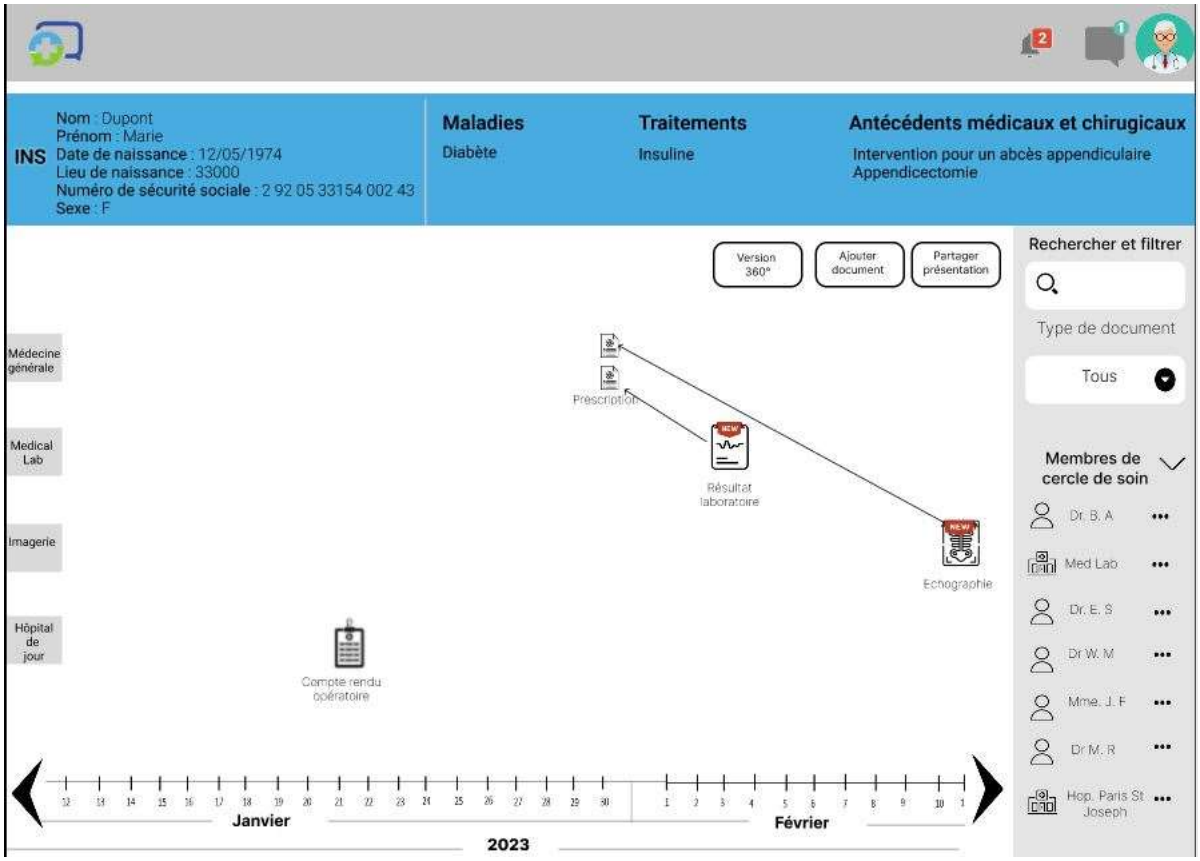


Figure 5 le système permet d'identifier les nouveaux documents et de pointer leurs éventuelles relations avec les anciens documents

Le système permet aussi au professionnel de santé d'effectuer des recherches en tapant des requêtes sur la zone de filtrage. Les documents qui répondent à la requête seront positionnés dans le premier plan de la visualisation. En même temps, les axes de la visualisation s'ajustent pour s'étendre sur la période de création de ces documents et pour inclure les personnes qui ont généré ces documents (Figure 6). Ensuite, si le professionnel de santé souhaite de garder les résultats de recherche pour les futures navigations, il sélectionne les documents concernés et crée un groupe qui décrit le problème traité par ces documents. Le groupe créé s'affiche dans le panel à gauche en dessous de la liste des professionnels de santé en permettant à l'utilisateur de le visualiser ou le partager. Par conséquent, quand le problème traité nécessite un travail coopératif pour le régler, le professionnel clique sur le bouton partager pour choisir le professionnel de santé concerné et le groupe sera partagé. Dans ce cas, quand ce deuxième correspondent accède au profil de patient, sa première visualisation affichera le groupe partagé en premier (Figure 7).

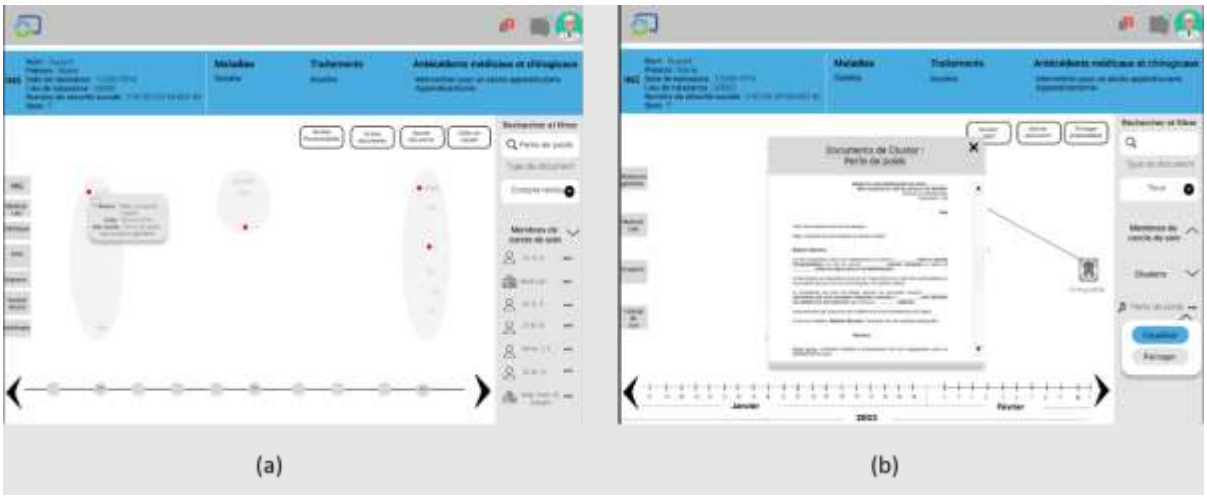


Figure 6 le système permet de grouper les résultats de la recherche: a) on commencer par parcourir les résultats et on sélectionne les documents pertinents. b) on crée un groupe qu'on peut visualiser et partager avec les autres correspondants.

CaseOverview permet aussi aux professionnels de santé d'échanger autour des documents, pour cela, il accède aux détails de document concerné et lance une discussion à partir de bouton « lancer une discussion ». Sur la fenêtre de discussion qui s'affiche, ils peuvent échanger sur le document, le patient et peuvent taguer les échanges pertinents pour les garder comme commentaires sur le document (Figure8)

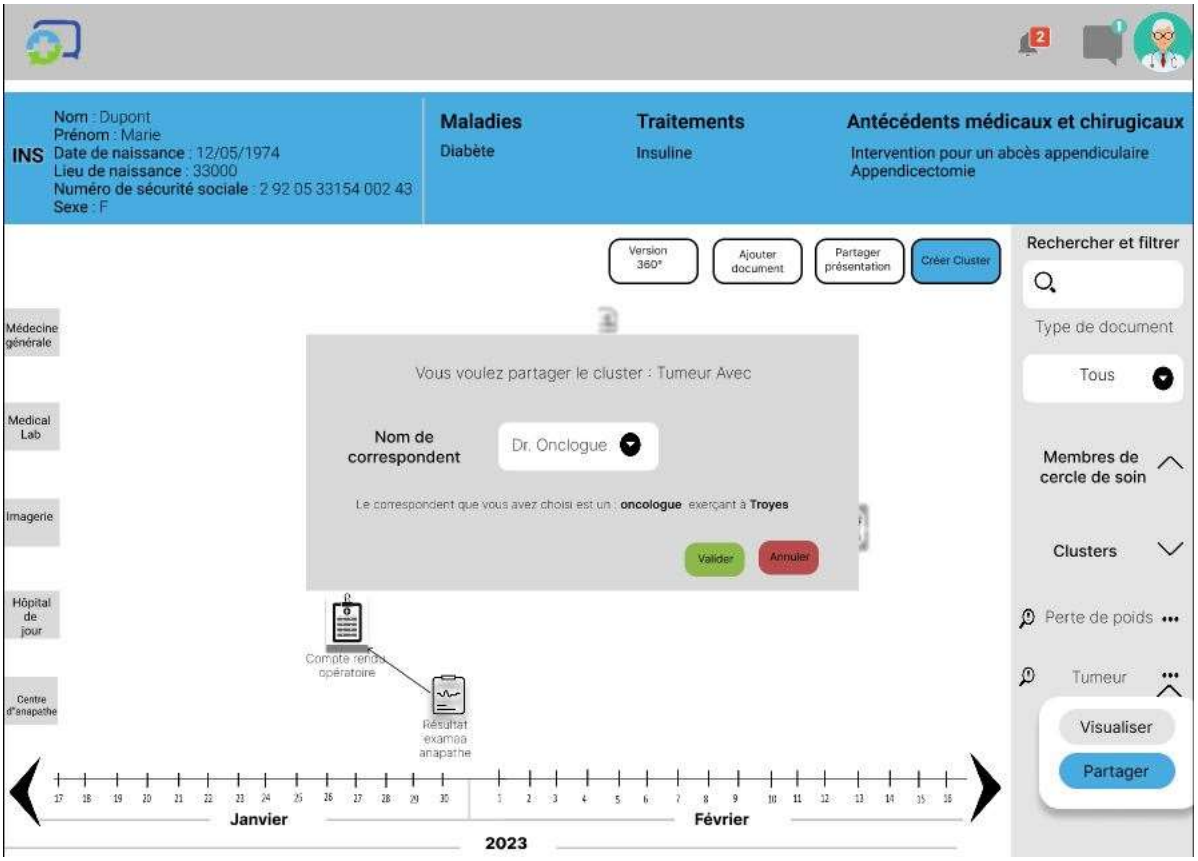


Figure 7 partager un groupe de document avec un correspondent

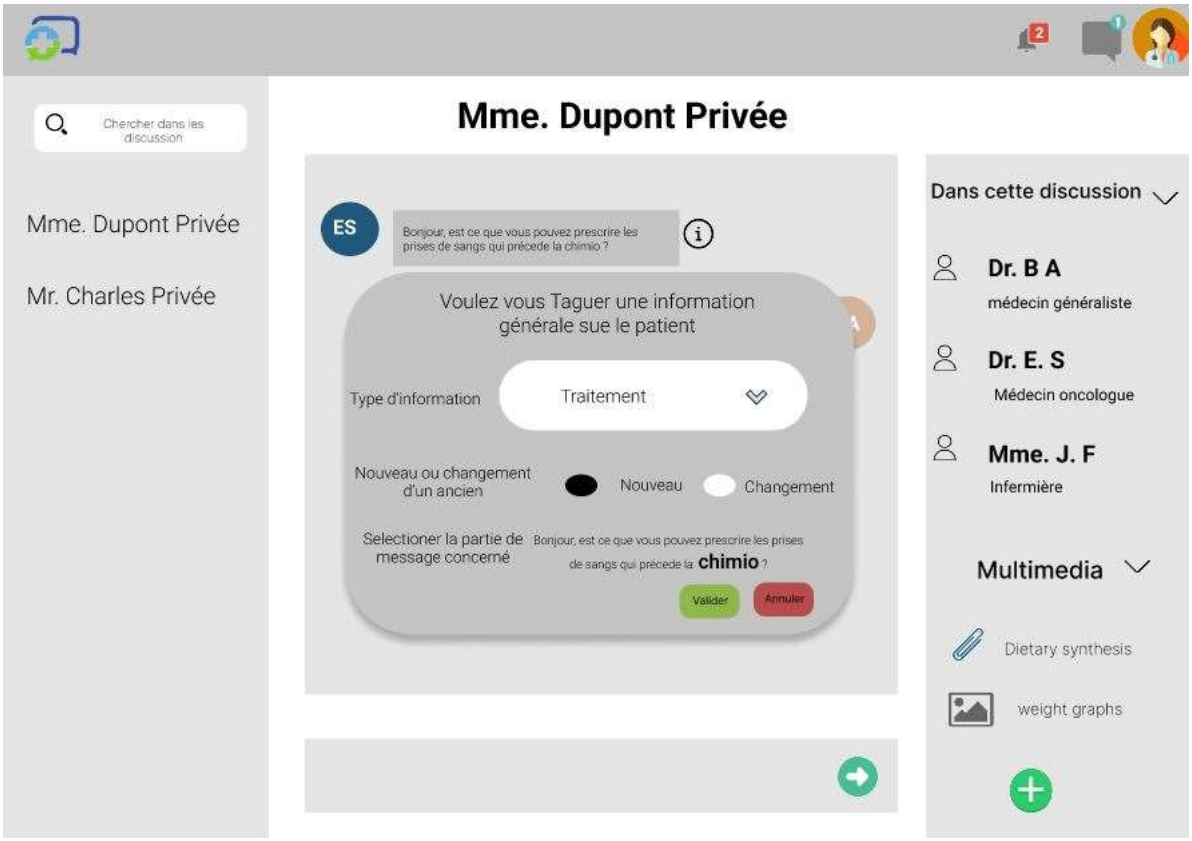


Figure 8 fenêtre d'échange autour de document

Évaluation

Pour évaluer notre modèle et les principes de conception sous-jacents, nous avons organisé une évaluation en deux itérations :

1) **Un atelier basé sur des scénarios** : nous avons invité sept professionnels de santé entre médecins et paramédicaux pour tester et discuter notre modèle. Nous avons utilisé un écran tactile et une tablette pour parcourir des scénarios d'usage et nous avons enregistré les discussions autour des différentes fonctionnalités.

2) **Une série d'entretiens individuels** : nous avons révisé notre modèle en intégrant les retours émanant du premier atelier et nous avons rencontré trois autres professionnels de santé pour récolter leurs retours par rapport au modèle et les révisions proposées. Nous avons utilisé un ordinateur pour parcourir les scénarios et nous avons enregistré les discussions.

L'analyse des données collectées a donné lieu aux résultats suivants :

a. **Offrir une vue d'ensemble globale** : les acteurs de soin se sont accordés sur l'intérêt de visualiser et d'identifier les différents documents pour repérer les tendances, suivre l'évolution des événements critiques et faciliter la création d'une vue d'ensemble d'un cas patient. En outre, ils ont accueilli favorablement l'idée de visualiser et de trouver tout ce qui a été échangé autour du patient sans avoir à télécharger ou à documenter des informations dans un autre système que les dossiers qu'ils utilisent actuellement. Cependant, ils ont évoqué les restrictions d'accès pour

respecter le secret médical et ont proposé de donner à chaque professionnel la possibilité de décider des droits d'accès pour chaque document.

b. **Soutenir la construction d'une vue d'ensemble situées** : bien que la vue d'ensemble globale du cas d'un patient soit utile pour comprendre son état de manière holistique, cela n'est pas toujours suffisante. Les acteurs de soins ont indiqué que le passage de la vue à 360° à leur vue d'ensemble situées leur permettait de se concentrer sur les problèmes qu'ils traitent. C'est pourquoi ils ont estimé que la fonction leur permettant de regrouper les documents qu'ils produisent et reçoivent, avec la possibilité de sélectionner d'autres documents pour améliorer leur propre vue d'ensemble, était précieuse.

c. **Soutenir l'awareness des activités:** le suivi de l'évolution des événements et des activités autour du patient a été perçue comme la caractéristique la plus importante du système. Tous les acteurs des soins ont affirmé que la reconnaissance des différentes rencontres les aidera à contextualiser et à mettre en corrélation leurs activités avec celles qui se déroulent au cours de la même période.

d. **Soutenir l'awareness sociale** : l'identification des autres participants dans la prise en charge des patients grâce au panneau fixe (à droite de l'écran) montrant l'équipe de soins, et l'axe des ordonnées mettant en évidence l'origine des documents ont été indiqués comme très importants pour contextualiser et améliorer la vue d'ensemble du cas d'un patient. De plus, les participants ont indiqué qu'il était pertinent d'identifier les acteurs de soins qui participent activement au traitement du patient et qui figurent en haut de l'axe des ordonnées.

Offrir une vue d'ensemble basée sur les problèmes : Les différents participants ont apprécié la possibilité de créer et de visualiser des "clusters". Ils ont estimé que la possibilité de classer les documents devrait faciliter l'identification des principaux problèmes et permettre d'obtenir une vue d'ensemble du cas du patient.

Conclusion

Dans cette thèse, nous avons adopté une approche de conception centrée sur les pratiques afin de définir une solution numérique pour accompagner la prise en charge de patients intégrés dans des parcours de soins.

Nos contributions sont à différents niveaux :

• **Contributions empiriques** : Nous proposons une description fine de la pratique de création des vues d'ensemble des patients, pratique située, orientée problème, et basée sur les documents et les interactions.

• **Contributions de conception** : Nous avons proposé des principes de conception pour des systèmes qui visent à soutenir la création d'une vue d'ensemble dans un contexte de coopération inter-organisationnelle.

• **Contribution instrumentale** : Nous avons proposé et évalué une mise en œuvre de ces principes de conception au travers de maquettes et de scénarios d'une solution de visualisation. Cette solution, basée sur les documents plutôt que les données, permet de s'intégrer dans l'écologie d'artefacts des acteurs et de leurs organisations plutôt que de proposer la conception d'un nouvel outil.

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Doctorat : Systèmes SocioTechniques

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Soutenir les parcours de soins par la visualisation des documents médicaux partagés et la communication

Les études en Travail Coopératif Assisté par Ordinateur (TCAO) ont montré l'importance de l'awareness pour dans la coopération. Dans un contexte de coopération inter organisationnelle (IOC), la dispersion des données et des acteurs rend cette awareness difficile. Pour cela, nous avons adopté une approche centrée sur les pratiques pour comprendre comment une vue d'ensemble est construite par des acteurs divers, afin de proposer une solution informatique correspondant aux pratiques. Notre cas d'étude est celui de la coopération entre acteurs de santé dans le contexte des parcours de soins coordonnés. Dans ce contexte, les acteurs de santé ont besoin de créer une vue d'ensemble du cas d'un patient pour être en mesure de le traiter. Notre analyse a montré que l'élaboration de cette vue d'ensemble est un processus dynamique et personnalisé qui se base à la fois sur des documents et des interactions. Sur la base de cette compréhension, nous avons défini des principes de conception que nous avons traduits en un modèle appelé CaseOverview. L'évaluation de ce modèle nous a permis de valider nos propositions : un système pour la IOC doit permettre de passer d'une vue globale à une vue détaillée, d'offrir des vues basées sur les problèmes, et de favoriser l'awareness. Ce travail contribue à la fois aux travaux menés en TCAO et en informatique médicale, en adoptant une approche sur les pratiques qui nous amène à une proposition originale de solution pour l'élaboration de vue d'ensemble d'un patent, qui se focalise sur le rôle significatif des documents et des interactions.

Mots clés : coopération interorganisationnelle – visualisation – parcours de soins coordonnés – TCAO – médecine, informatique.

Supporting Integrated Care through Visualization of Shared Medical Documents and Communication

The demand for inter-organizational cooperative (IOC) problem-solving is increasing. CSCW studies advocated the centrality of awareness to foster this cooperation. Yet, stakeholders and data fragmentation impede gaining this awareness. Studies suggested that furnishing stakeholders with overview displays helps them comprehend dispersed activities and align their work. However, in IOC, stakeholders come from diverse backgrounds and have different practices, and information needs, making a stable presentation ineffective. To address this, we adopted a practice-centered computing approach to investigate the practices allowing to achieve an overview to inform the design of technological solutions. Therefore, we conducted a case study focusing on achieving an overview of a patient's case within an integrated care context. Results showed that overview is: 1) a dynamic, individualist process, 2) based on shared documents and communication, and 3) used differently according to the situation. Based on those results, we defined design implications to support achieving an overview in IOC and translated them into a model called CaseOverview. The evaluation showed that systems should allow a shift from comprehensive to situated overviews, offer problem-based overviews, and support temporal and social awareness. This work contributes to the CSCW and health informatics communities by participating in the ongoing discussion on overviews and emphasizing the need to consider a practice-centered approach and the significant role of documents in visualizing overviews.

Keywords: inter-organizational cooperation – visualization – integrated care – CSCW – medical informatics.

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Ecole Doctorale "Sciences pour l'Ingénieur"