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## Supporting collaboration in knotworking: a design case study in home care

Khuloud Abou Amsha

► **To cite this version:**

Khuloud Abou Amsha. Supporting collaboration in knotworking: a design case study in home care. Sociology. Université de Technologie de Troyes, 2016. English. NNT : 2016TROY0011 . tel-03361807

**HAL Id: tel-03361807**

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Thèse  
de doctorat  
de l'UTT

**Khuloud ABOU AMSHA**

**Supporting Collaboration  
in Knotworking –  
a Design Case Study in Home Care**



**Spécialité :**

**Ingénierie Sociotechnique des Connaissances, des Réseaux  
et du Développement Durable**

2016TROY0011

Année 2016

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# THESE

*pour l'obtention du grade de*

## DOCTEUR de l'UNIVERSITE DE TECHNOLOGIE DE TROYES

**Spécialité : INGENIERIE SOCIOTECHNIQUE DES CONNAISSANCES,  
DES RESEAUX ET DU DEVELOPPEMENT DURABLE**

*présentée et soutenue par*

**Khuloud ABOU AMSHA**

*le 18 mai 2016*

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### **Supporting Collaboration in Knotworking - a Design Case Study in Home Care**

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# Acknowledgements

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I would like to thank my supervisor Professor Myriam Lewkowicz for her tremendous enthusiasm, commitment and excellent supervision during the period of this work.

I am also grateful for my thesis reporters, Professor Rémi Bastide and Professor Yannick Prié, for examining my work and their insightful comments and also for my committee members, Professor Erik Grönvall, Professor Pascal Salembier, and Dr. Vincent Rialle, for their interest in the work and stimulating questions.

Furthermore I would also like to acknowledge with much appreciation the crucial role of the members of “e-maison medicale” association, particularly Dr. Didier Cloos and Mr. Jean Sébastien Schwartz, who dedicated a lot of their precious time and effort to help me to understand the complexity of the home care activities.

My thanks and appreciations also go to my parents, my brother Khalil and my beloved husband Amjad for the support and encouragement they gave when times got rough.

Finally, this research was supported by a grant from the Regional Council of Champagne Ardenne (convention n° E201207353).

I am most grateful for all these contributions.

# Abstract

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The development of new modes of working raises new challenges for supporting collaboration. Knotworking represents an innovative way of organizing work where collaboration occurs in episodes depending on the requirement of the current situation. Our study investigates the collaborative practices in such context and how to computer-support them. Supporting collaboration in knotworking presents multiple challenges due to the episodic, improvised, and cross-boundary nature of the collaboration. These challenges were addressed partially in the CSCW literature. However, we claim that supporting knotworking needs more investigation. The problem can be divided into two parts: First, it has not been clearly established how actors involved in a knotworking process organize their work and collaborate. Second, it is not clear how collaborative applications should be designed to accommodate knotworking. Our objective in this thesis is to tackle these challenges. Thus, we conducted a design case study investigating the collaborative practices of a group of self-employed care professionals who take care of patients at home. The results show: 1) the centrality of the coordinative artifacts for sharing information and coordinating the work. 2) How focusing on patients' quality of life leads care actors to address issues beyond the medical scope. 3) How care actors experience different rhythms of collaboration depending on the patient's situation. Based on these results, we defined some implications for design to support this type of care ensembles. Guided by these principles, we developed the CARE application (Classeur pour une Approche en Réseau Efficace), which is accessible via a tablet and designed to stay at the home of the patient. Feedback reveals the potential role of technologies in motivating the participation of new care actors, and in the creation of a shared place for diverse participants. Our work contributes to CSCW by bringing to focus a new model of organizing work named knotworking and by providing a first design case study aiming at supporting collaboration in this context.

**Keywords:** Collaboration; knotworking; home care; CSCW;

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# 1 INTRODUCTION

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For more than thirty years, Computer-Supported Cooperative Work (CSCW) focuses on understanding and augmenting the social activity with technologies (Schmidt and Bannon 2013). Many researchers have worked on the challenging task of narrowing the socio-technical gap, defined by Ackerman (2000) as the gap between how we should support the social activity and what technologies can offer. In the research work that we are presenting here, we are taking the same stance, as we investigate a new way of organizing work and collaboration, called knotworking.

The term knotworking was introduced by Engeström and his colleagues to describe a cross-boundary way of organizing work and collaboration (Engeström, Engeström, and Vähääho 1999). In knotworking, collaboration occurs in episodes depending on the requirement of the current situation. The persons involved in a knotworking process create and take part into improvised collaboration groups - called knots - that gather otherwise loosely connected actors.

Knotworking rises and proliferates in conjunction with ongoing changes in work and its organization, particularly the emergence of the co-configuration work identified by (Victor and Boynton 1998).

*"When a firm does co-configuration work, it creates a product that can learn and adapt, but it also builds an ongoing relationship between each customer -product pair and the company. Doing mass customisation requires designing the product at least once for each customer. This design process requires the company to sense and respond to the individual customer's needs. But co-configuration work takes this relationship up one level- it brings the value of an intelligent and 'adapting' product. The company then continues to work with this customer-product pair to make the product more responsive to each user. In this way, the customisation work becomes continuous. Unlike previous work, co-configuration never results in a 'finished' product. Instead, a living, growing network develops between customer, product, and company." (Victor and Boynton 1998, 195)*

Thus, to achieve co-configuration work, it is vital to establish a relationship with the customer and facilitate the continuous interaction.

*"With the organization of work under co-configuration, the customer becomes, in a sense, a real partner with the producer." (Victor and Boynton 1998, 199)*

Therefore, implementing co-configuration is based on creating a system including three components: the client, the product/service, and the company (Victor and Boynton 1998). This system can be extended to include the various producers who cooperate to deliver the product/service (Engeström 2000).

In this context, knotworking provides an innovative way for professionals and their client to create temporally 'knots' to work on a shared object (Engeström, Engeström, and Vähääho 1999). From our point of view, knotworking emerges as an attempt to accommodate the complexity of interactions required in recent modes of production such as co-configuration.

Supporting collaboration in a knotworking process presents multiple challenges due to the episodic, improvised and cross-boundary nature of the collaboration. Some of these challenges were addressed partially in the CSCW literature under banners such as supporting the collaboration in loosely coupled workers (Pinelle and Gutwin 2003) or supporting collaboration across organizational boundaries (Mark S. Ackerman 1996; Stevens and Wulf 2002; Ackerman et al. 2013). However, we claim that supporting knotworking needs more investigation as it has not been explicitly studied in CSCW literature, and it is not clear what the design requirements are to support this process, or how systems should be designed to address the needs of actors involved in such process.

Many studies referred to knotworking as a potential theoretical framework to address issues related to the development of organization of work in complex contexts, like inter-professional care teams (Varpio et al. 2008; Bleakley 2013; Barrow et al. 2014). However, studies using the knotworking concept to inform the design of technologies to support this pattern of cooperative work are lacking. In fact, though the knotworking concept depicts an interesting form of work, still the description does not explicit how collaboration occurs. The knotworking concept does not address essential questions like: how actors involved in the knotworking process communicate, share information and handle interdependencies? Moreover, the improvised nature of collaboration in knotworking rises the question of the motivation to form a 'knot' and how to support the unpredictable cooperation through the process of knotworking, i.e. before the creation of a knot and after the dissolving of a knot.

The problem can be divided into two parts:

First, it has not been clearly established how members involved in a knotworking process organize their work and collaborate. Despite the empirical origins of the knotworking concept and all the examples of knotworking provided by Engeström and his colleagues, the main characteristics of collaboration in this context remain vague. More efforts are required to help identify a knotworking process and what are the conditions for a sustainable knotworking process.

Second, it is not clear how collaborative applications should be designed to accommodate the knotworking process. The question is to explore what technologies can offer and how to implement technology without hindering the knotworking process.

Our objective in this thesis is to investigate collaboration practices of people involved in knotworking to design technologies supporting this kind of collaboration.

To explore the challenges related to collaboration in a knotworking process, we conducted a case study investigating the collaboration practices of a group of French self-employed care professionals organized as an association named "e-maison médicale", in the city of Troyes.

In fact, the French healthcare sector, and particularly the primary sector, is facing socioeconomic challenges, challenges being aggravated by the lack of health

professionals in some geographic areas. Thus, policy makers push for the integration of the health and social care services, which creates a climate for innovative initiatives for providing healthcare and particularly at home. Moreover, the domain of home care, particularly when provided as substitution to placing the patient in a health care setting, provides a good example of knotworking where evolving actors with different professions cooperate to accommodate the evolution of the patients' needs.

The "E-maison médicale" association promotes collaboration among the different care actors around patients at home. Their objective is to preserve the quality of life of patients and their relatives. We argue that the organization of work in this association provides an example of knotworking because the care actors adapt their work according to the evolving situation of the patient. Also, the combination of care actors might change to address different aspects of care activities. Thus, collaboration occurs among evolving actors around a shared objective: "preserving the quality of life of the patient".

This association is very successful in the sense that it allows patients who want to stay at home with their family to do so. However, its members are facing a huge work overload, and express frustration at being unable to share and extend their collaborative model to more care actors and more patients. We make the hypothesis (together with the founders of this association) that a computer-based system could help them managing their collaborative work in a more stable and sustainable way. However, for so doing, this system has to be aligned with their organization of work and collaboration.

To understand the collaborative practices that are taking place among the members of the e-maison médicale association, we used ethnographic methods (Randall, Harper, and Rouncefield 2007). We are following a long tradition in the CSCW domain where researchers use ethnographies and other kinds of fieldwork studies to understand the current organization of work and how to design and integrate technologies without disturbing the current practices (Schmidt and Bannon 2013). Using ethnographic methods for studying work shows the real-world character and context of work and ensures that system design resonates with the circumstances of its use (Randall, Harper, and Rouncefield 2007). However, one issue stems from drawing on case studies, which is the difficulty of generalizable consequence and the creation of generic systems. In CSCW, the theme of generalization is perused often through building a set of related and structured concepts that might provide reusable tools for in all CSCW investigations and elsewhere (Randall, Harper, and Rouncefield 2007).

Recently, (Wulf et al. 2011) proposed a three-phase research approach that they call a design case study. For them, a design case study starts with analyzing empirically the practices in a particular field of application, then designing an ICT artifact depending on the findings, implementing it and investigating the appropriation of the technical artifact over an extended period of time. They propose the "design case study" as a theoretical framework that deals with the entire development and appropriation cycle.



Such a framework, they believe, will allow transferring findings concerning the design of innovative artifacts and their appropriation in social practice.

They illustrated, through a presentation of their research program in the University of Siegen, how the growing corpus of design case studies allows identifying cross-cutting themes, comparing the context-specific findings, building terminology, and developing abstractions as elements of a theory of practice-based computing.

In this context, our work is an attempt to offer a design case in the domain of home care in which involved actors organize their work and collaborate by forming knots.

We conducted the case study over a period of fifteen months. Inspired by the grounded theory approach (Glaser and Strauss 1967), the results of our data analysis guided our further data collection. We combined interviews and observation, together with a discussion session on the use of actual coordinative artifacts and two design workshops with care actors.

The results show:

- The centrality of the coordinative artifacts (e.g. a liaison notebook) for sharing information and coordinating the work.
- How focusing on patients' quality of life leads care actors to address issues beyond the medical scope.
- How team members experience different rhythms of collaboration depending on the patient's situation.

This case study also permitted to identify challenges related to:

- Integrating new care actors.
- Sustaining the ongoing negotiation of role and tasks.
- Motivating the engagement of all care actors.

Based on these results, and motivated by the goal to tackle the listed challenges, we defined some implications for design to support this type of care ensembles. Guided by these principles, we developed the CARE application (Classeur pour une Approche en Réseau Efficace), which is accessible via a tablet and designed to stay at the home of the patient. All the care actors around a patient can use the application, and the patients keep the tablet with them when going for a consultation. We placed tablets in the homes of five patients for five months. The CARE application represents the technological component of a socio-technical solution that we suggest to support knotworking in the case of e-maison médicale. Feedback reveals the potential role of technologies in motivating the participation of new care actors, and in the creation of a shared place for diverse participants.

Our work participates in extending the scope of CSCW to include this new model of organizing work named knotworking, where the challenge is to support a collaboration process beyond the people currently involved, and where the center of the organization

keeps shifting to address the unstable object/motive. Our case study in the home care domain provides insight into the complexity and the challenges related to supporting collaboration in this knotworking context, and our proposed solution represents an attempt to prop our insights.

The rest of this dissertation is organized as follows:

**Chapter 2** presents a discussion of the literature that is relevant to the research questions we are dealing with. We start with introducing the knowworking concept with a focus on the characteristic of collaboration in a knotworking process. Then we review the literature of Computer Supported Cooperative Work (CSCW) and we highlight the issues addressed in this domain. Next we focus on the CSCW literature in the context of home care and we highlight the particularity of cooperation in such context. Finally, we conclude the chapter with a synthesis of the all the reviewed literature based on their relevance to our research questions.

**Chapter 3** describes our case study. We start providing element of context related to home care in France and to the association we are observing (e-maison médicale). Then, we describe the methodology we followed for data collection and analysis. Finally, we present and discuss our results of the fieldwork.

**Chapter 4** presents the socio-technical system we have developed to support the knotworking of e-maison médicale. We first describe the design principles that are grounded in our fieldwork, and the translation of these principles into mockups. We then present the features of the CARE application illustrated with scenarios. Finally, we describe the pilot study and report on the feedback.

**Chapter 5** concludes the thesis by summarizing its contributions and discussing future work.

## **2 LITERATURE REVIEW**

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To support knotworking with technologies, we need to understand what are the characteristics of collaboration in this context. Thus, we start by presenting the knotworking concept and its origins. Then, we turn to a review of the main issues and concepts developed in the literature of Computer supported Cooperative Work (CSCW) to help us describe knotworking as a pattern of cooperative work. This review also helps us to identify issues related to the complexity of supporting cooperative work and ways it has been supported so far. Finally, we focus on the literature related to collaboration in the home care domain, as it is the focus of our case study. The objective is to explore what has been investigated related to collaboration in home care and the technologies used to support it, to both inform our own investigation and better position our contribution.

## 2.1 KNOTWORKING

In their work, (Engeström, Engeström, and Vähäaho 1999) introduced the concept of knotworking to depict work situations that require the “active construction of constantly changing combinations of people and artefacts over lengthy trajectories of time and widely distributed space” (p. 345).

This type of work is an intense collaborative activity that relies upon frequently changing combinations of people coming together to undertake tasks of relatively brief duration. This combination is called a knot.

*“the knot symbolizes a rapidly pulsating, distributed and partially improvised collaboration between loosely connected actors and activity systems” (Engeström 2000, p.972)*

Thus, the notion of a knot does not fit conventional definition of a team, which is typically understood to be a stable configuration, nor do they resemble the kind of pre-existing networks that workers might exploit.

The authors emphasize that knotworking represent an object-orientated, situation directed, and highly distributed activity:

*“Knotworking is not reducible to a single knot, or a single episode. It is a temporal trajectory of successive, task-orientated combinations of people and artefacts ...fragile because they rely on fast accomplishment of intersubjective understanding, distributed control and co-ordinated action between actors who otherwise have relatively little to do with each other ...In knotworking, the combinations of people and the contents of tasks change constantly.” (Engeström, Engeström, and Vähäaho 1999, 352–353).*

As knotworking represents a pulsing, unstable, distributed and improvised collaborative work, the authors argues that “the center does not hold”(p. 346): the knot of collaborative work cannot be reduced to any particular individual or organizational center of control. Instead, “the locus of initiative changes from moment to moment within a knotworking sequence” (p. 346).

*“The tying and dissolution of a knot of collaborative work is not reducible to any specific individual or fixed organisational entity as the center of control ...The unstable knot itself needs to be made the focus of analysis.” (Engeström et al, 1999, pp. 346-347)*

As a result, the analysis of such collaborative work cannot assume a central coordinator or locus of control, nor can it assume a central “additive sum of the separate perspectives of individuals or institutions” (Engeström, Engeström, and Vähääho 1999, 346–347). Instead, in knotworking, “the unstable knot itself needs to be made the focus of analysis” (Engeström, Engeström, and Vähääho 1999, p.347). Since the combination of people and the contents of tasks are always unstable, the importance of communication systems and artefacts cannot be underestimated to the success of knotworking.

Furthermore, the knot performs a tightly interconnected set of actions, and is capable of deliberately organizing and dissolving itself to perform and/or terminate actions. In this way, “the knot function[s] as a self-conscious agent” (Engeström, Engeström, and Vähääho 1999, p.352). In knotworking, “the subject is not fixed – the subject is the pulsating knot itself, or in other words, subjectivity is dynamically distributed within the knot” (p. 352). Again, the subject, as the assumed center, does not hold.

Finally, knotworking cannot be reduced to a single episode or a single knot. Knotworking is “a temporal trajectory of successive task-oriented combinations of people and artefacts” (Engeström et al., 1999, p. 352).

*“Knotworking, is a longitudinal process in which knots are formed, dissolved, and re-formed as the object is co-configured time and time again, typically with no clear deadline or fixed end point” (Engeström 2000, 973).*

Knotworking suggests a new way to organize work and collaboration, and supporting this kind of collaboration with technologies needs further investigation. In the next section, we turn to the CSCW literature to better understand what are the implications related to supporting collaboration in knotworking.

## 2.2 COMPUTER SUPPORTED COOPERATIVE WORK (CSCW)

CSCW investigates how computer-based systems can be designed to reduce the complexity of coordinating cooperative activities that are individually conducted and yet interdependent (Schmidt and Bannon 1992). The field gathers researchers from different disciplines endeavoring to understand cooperative work practices with a view to developing adequate computational technologies to assist cooperative work, mediate communication, and support the regulation of coordinative practices (Schmidt and Bannon 2013).

For CSCW researchers, the term “Cooperative work” designates multiple persons working together to produce a product or service (Bannon and Schmidt 1989). The definition conveys that the boundaries of the cooperative work process are defined by actual cooperative behavior and are not necessarily fitting with the boundaries of formal organizations. Thus, a cooperative work process may cross company boundaries and may involve partners in different companies at different sites, each of the partners producing a component of the finished product (Bannon and Schmidt 1989).

According to Kjeld Schmidt (Schmidt 1990), a cooperative work arrangement may emerge in response to different requirements: 1) to augment the mechanical and information processing capacities of human individuals to accomplish a task. 2) To combine the specialized activities of several workers devoted to the operation of different specialized tools, techniques, or routines. 3) To facilitate the application of multiple problem-solving strategies and heuristics to a given problem to balance the potential individual biases. 4) To facilitate the application of multiple perspectives and conceptions on a given problem so as to match the multifarious nature of the work environment.

People engaged in a cooperative work process are mutually dependent in their work and have to cooperate to get the work done (Schmidt 1991).

*"Being mutually dependent in work means that A relies positively on the quality and timeliness of B's work and vice versa and should primarily be conceived of as a positive though by no means necessarily harmonious, interdependence (Schmidt and Bannon 1992, p.13).*

This interdependence makes that any cooperative effort requires many secondary activities of negotiating and controlling these cooperative relationships. Thus, the cooperating workers have to articulate their distributed individual activities (Strauss et al. 1985; Gerson and Star 1986; Strauss 1988), which includes tasks like divide, allocate, coordinate, schedule, mesh, interrelate, etc. (Schmidt and Bannon 1992).

To support cooperative work, CSCW draws upon the whole field of computer science in its search for applicable techniques. However, what distinguishes CSCW from other (technology-driven) domains is the focus on the cooperative work, which motivated conducting many ethnographic and other in-depth studies to gain insights into the practices of people cooperating with each other and with the computer technologies

(Greif 1988). The use of ethnographic methods for studying work promotes the real-world character and context of work, and ensures that the system design resonates with the circumstances of its use (Randall, Harper, and Rouncefield 2007). The focus of CSCW is not the necessity of conducting requirements analysis as part of the process of designing a particular system for a particular setting, through including a collection of more or less well-known technologies, but doing workplace studies for the purpose of developing new technologies. Thus, the aim is to make fieldwork an integral part of the conceptual work essential to technological research (Schmidt 2009). Hence, ethnographic and other in-depth workplace studies contribute conceptually by providing a set of related and structured concepts that might provide researchers with reusable tools for the investigations in CSCW and elsewhere (Randall, Harper, and Rouncefield 2007).

The way CSCW addresses the design of computer systems is also particular. While the design of conventional computer-based systems for work setting aims at developing effective computational models that capture the structures and processes existing in the field of work (data flows and knowledge representations), and developing adequate ways of presenting and accessing these structures and processes as represented in computer systems (user interface, functionality), CSCW addresses design issues related to how multiple users articulate their individual activities to carry out their work (Schmidt and Bannon 1992).

### **2.2.1 Articulation Work**

Scholars in CSCW make a distinction between two types of work: 'cooperative work' and 'articulation work' (Schmidt 1994). While cooperative work includes work process related to production of a product or a service, the articulation work refers to the informal work necessary to ensure smooth coordination and to manage the distributed and contingent nature of work (Strauss et al. 1985).

Cooperative work has a distributed nature, which should be managed to handle the interdependencies of distributed activities. The articulation work arises as a set of activities necessary for managing the distributed nature of cooperative work.

*" [Articulation work is] a kind of supra-type of work in any division of labor, done by the various actors" (Strauss 1985, 8).*

Thus, the participants in a cooperative work arrangement have to communicate to be able to articulate their distributed activities. The technological communication facilities, like file sharing, email and video conferencing, provide a powerful repertoire of everyday social interaction despite the distance. However, this is only useful for a small and relatively stable cooperating ensemble; in 'real world', cooperative work settings involve a broad, varying, or an indeterminate number of participants. In these settings, articulation work becomes extremely complex; therefore, people apply what (Schmidt and Bannon 1992) calls "*mechanisms of interaction*" to reduce the overhead cost of articulation work. Examples of these mechanisms include organizational structures,

plans, schedules, standard operating procedures (Suchman 1983; Suchman and Wynn 1984) and conceptual schemes (e.g. taxonomies) (Star and Griesemer 1989; Bowker and Star 1991).

However, these mechanisms represent local and temporary closures, and, thus, require articulation work themselves.

*“Every real world system thus requires articulation to deal with the unanticipated contingencies that arise. Articulation resolves these inconsistencies by packaging a compromise that 'gets the job done', that is closes the system locally and temporarily so that work can go on” (Gerson and Star 1986, 266).*

Thus, the relation between cooperative work and articulation work is recursive.

*“Articulation work is a recursive phenomenon in that the management of an established arrangement of articulating a cooperative effort may itself be conducted as a cooperative effort which, in turn, may also need to be articulated” (Schmidt and Simone 1996, 159).*

The research efforts in CSCW raised a set of issues related to supporting the ongoing articulation of distributed activities, and the cooperative control of the mechanisms of interaction themselves (Schmidt and Bannon 1992).

### **2.2.2 Supporting Articulation Work**

A core issue in CSCW is how to support the articulation work that people must engage in to make the cooperative mechanisms fit together and fit local circumstances.

In fact, the dynamic environment of work drives the continuous negotiation of task allocation and articulation, which makes the traditional formal organization chart - presumed to present the actual pattern of authority, information flow, and communication - inadequate for analyzing and modeling the articulation of real world cooperative work arrangements.

Many studies of office work emphasize that co-workers engage in complex forms of cooperative decision-making to establish routine activities, regardless of their position and authority, (Suchman 1983; Gerson and Star 1986).

*“the procedural structure of organizational activities is the product of the orderly work of the office, rather than the reflection of some enduring structure that stands behind that work” (Suchman 1983, 321).*

This observation illustrates the discrepancy between the office procedures - supposedly governing office work - and the practical action carried out by office workers. The office procedures require problem-solving activities and negotiation with co-workers. Thus, the 'informal' interactions that take place in the office are crucial to the actual conduct of the work process itself.



Hence, computer systems supporting work should consider not only the information flow but also the articulation work required to make the flow possible. In other words, computer-supported cooperative work should aim at favoring the self-organization of the cooperative ensembles, as opposed to computerizing formal procedures that will disrupt cooperative work.

(Schmidt and Bannon 1992) argue that an application supporting cooperative work should consider, in addition to the work-related functionalities, facilities that allow users to negotiate task allocation and articulation. Aligned with this position, (Robinson 1991) states that a CSCW application should support at least two interacting "levels of language" as a condition "for fruitful co-operation".

*"In general it can be said that any non-trivial collective activity requires effective communication that allows both ambiguity and clarity. These ideas of ambiguity and clarity can be developed as the 'formal' and 'cultural' aspects of language as used by participants in projects and organizations. 'Computer support' is valuable insofar as it facilitates the separation and interaction between the 'formal' and the 'cultural.' Applications and restrictions that support one level at the expense of the other tend to fail.*

*The formal level is essential as it provides a common reference point for participants. A sort of 'external world' that can be pointed at, and whose behaviour is rule-governed and predictable. The 'cultural' level is a different type of world. It is an interweaving of subjectivities in which the possible and the counterfactual [...] are as significant as the 'given.' [...] The formal level is meaningless without interpretation, and the cultural level is vacuous without being grounded. "(Robinson 1991, 43)*

The organizational procedures present heuristic and vague statements that workers have to interpret, instantiate, and implement. For example, (Suchman 1987) in her work on the role of plans in situated action, illustrates how they serve a heuristic function:

*"Plans are resources for situated action, but do not in any strong sense determine its course. While plans presuppose the embodied practices and changing circumstances of situated action, the efficiency of plans as representations comes precisely from the fact that they do not represent those practices and circumstances in all of their concrete detail. (Suchman 1987, 52)*

Hence, when designing CSCW applications, organizational models are conceived as resources for competent and responsible workers.

*"The system should make the underlying model accessible to users and, indeed, support users in interpreting the procedure, evaluate its rationale and implications. It should support users in applying and adapting the model to the situation at hand. It should allow users to tamper with the way it is instantiated in the current situation, execute it or circumvent it, etc. The system should even support users in modifying the underlying model and creating new models in accordance with the changing organizational realities and needs." (Schmidt and Bannon 1992, 26)*

Another way to support cooperative work is by building a Common Information Space (CIS) where members of the cooperative ensemble share documents and information about the work done together. This allows the members to interact without the constraints of prescribed procedures or established conventions.

*"... the focus is on how people in a distributed setting can work cooperatively in a common information space - i.e. by maintaining a central archive of organizational information with some level of 'shared' agreement as to the meaning of this information (locally constructed), despite the marked differences concerning the origins and context of these information items. The space is constituted and maintained by different actors employing different conceptualizations and multiple decision making strategies, supported by technology." (Schmidt and Bannon 1992, 22)*

Thus, the CIS represents a set of information that members can perceive, access, and manipulate. However, the members have to work together to agree on the interpretation of the shared information.

*"Cooperative work is not facilitated simply by the provision of a shared database, but requires the active construction by the participants of a common information space where the meanings of the shared objects are debated and resolved, at least locally and temporarily. Objects must thus be interpreted and assigned meaning, meanings that are achieved by specific actors on specific occasions of use." (Schmidt and Bannon 1992, 27)*

Thus, a common archive or shared database, where members can keep and modify the information, does not represent a Common Information System.

*"The material representation of information in the common space (e.g., a letter, memo, drawing, file) exists as an objective phenomenon and can be manipulated as an artifact. The semantics of the information carried by the artifact, however, is, put crudely, 'in the mind' of the beholder, and the acquisition of information conveyed by the artifacts requires an interpretive activity on the part of the recipient." (Schmidt and Bannon 1992, 27)*

Thus, when the cooperative work environment increase in complexity, supporting the articulation work should extend the focus form augmenting the communication to support "interaction mechanisms" or CIS.

Many studies undertaken within CSCW emphasize the central roles that artifacts plays in managing and coordinating information flow and work activities (J. S. Brown and Duguid 1994; Hanseth and Lundberg 2001; Luff, Heath, and Greatbatch 1992; Heath and Luff 1996; Svenningsen 2002). According to these studies, artifacts enable actors to coordinate their activities and have a general idea of the work progress; thus, they play a major role in cooperative work. Examples of artifacts include, for instance, to-do lists where actors will mark whenever they accomplish a task, procedures describing the

order in which tasks will be performed. The purpose of these artifacts is to reduce the quantity of articulation work.

As explained earlier, to limit the complexity of articulation work, people develop mechanisms of interaction such as divisions of work, routines, and conventions. In some cooperative settings, the established mechanisms of interaction are usually associated with multiple artifacts to form what (Schmidt and Simone 1996) have called "Coordination mechanisms". In the following, we will present the concept of "Coordination Mechanism" as we think it is an interesting framework to help us analyze the cooperative work we are investigating in our case.

### **2.2.3 Coordination Mechanisms**

The concept of coordination mechanisms was introduced by (Schmidt and Simone 1996) as a generalization of phenomena described in numerous empirical investigations of the use of artifacts for coordination in different work domains.

*"A coordination mechanism is a construct consisting of a coordinative protocol (an integrated set of procedures and conventions stipulating the articulation of interdependent distributed activities) on the one hand and on the other hand an artifact (a permanent symbolic construct) in which the protocol is objectified." (Schmidt and Simone 1996, 165–166)*

The role of the coordinative protocols varies from weak stipulations, as exemplified by "a map", to strong stipulations, exemplified by "a script". Also, whether weak or strong, a coordinative protocol will, certainly, encounter situations where it is beyond its bounds; therefore, actors must deviate from or circumvent the execution of the protocol.

The artifact in a coordination mechanism has a fundamental role in objectifying and giving permanence to the coordinative protocol; thus, allowing actors to access the stipulation of the protocol. Also, the artifact in some cases represent the state of the execution of the protocol and may thereby, among actors, mediate information about state changes to the protocol as it is being executed. Furthermore, the material format of the artifact provides a 'shared space' for mediating changes to the state of the protocol.

Coordination mechanisms are constructed to support certain aspects of the articulation of distributed activities within a particular cooperative work arrangement; thus, the use of a coordination mechanism may require aligning with other mechanisms devoted to different aspects of the articulation of those activities or to related activities.

#### **2.2.3.1 Computational Coordination Mechanism**

Coordination mechanisms based on paper artifacts (e.g., forms, catalogs, timetables) are used on a massive scale in modern work settings. While mundane, they have crucial affordances; nonetheless, such mechanisms have serious inherent limitations

concerning the propagation of the changes and the alignment of multiple coordination mechanisms.

The development of modern industries, services, and administrative organizations increased the need to operate in flexible and yet highly coordinated fashion; this represented a real challenge for conventional coordination mechanisms. In this context rises the idea of developing computational coordination mechanisms that address the limits of the conventional coordination mechanisms.

*"A computational coordination mechanism can be defined as a software device in which the artifact (in the sense of a permanent symbolic construct) as well as aspects of the protocol are incorporated in such a way that changes to the state of the protocol induced by one actor are conveyed, in accordance with the protocol, by the computational artifact to other actors."(Schmidt and Simone 1996, 183)*

(Schmidt and Simone 1996) identify two categories of requirements for computational coordination mechanisms: the 'malleability' and the 'linkability.'

Malleability means making the protocol of the coordination mechanism accessible by actors for modification to cope with the changing organizational requirements. The actors can decide to temporarily modify the behavior of the coordination mechanism to address contingencies. Finally, for actors to be able to define, specify, and control the execution of the coordination mechanism, the protocol must be intelligible to actors, that is, they can establish relationships between components of the mechanism and the field of work as represented by the data structures and functionalities of the target applications.

Linkability means that a computational coordination mechanism should be constructed in such a way that it can be linked to other coordination mechanisms in its organizational context. To ensure comprehensive linkability of computational coordination mechanisms, a general notation for constructing computational coordination mechanism is required.

The established mechanisms of coordination fit work settings that can be regulated through a stable workflow for example (working in chemical plants or factories). Other kinds of work processes cannot be regulated by routines and procedures entirely, for example, providing health care for patients, as it involves complex collaboration between multiple actors and institutions. Therefore, in complex cooperative work settings, in addition to 'first order' articulation work that often achieved through the use of established coordination mechanisms, actors have to carry out a 'second order' articulation work to accommodate contingencies in the course of work (Schmidt 2002); consequently, actors conduct articulation through ad hoc coordinative talking and mutual awareness of the activities of colleagues (Heath and Luff 1992; Heath et al. 2002; Schmidt 2002). To conclude, the CSCW literature offers rich insights into the complexity of supporting collaborative work. We have explored interesting concepts that help us to better describe and understand the collaboration in knotworking (section 2.1).

## **2.3 SUPPORTING COLLABORATION IN HOME CARE**

Home care has progressed to comprise not only the conventional health professionals but also the social workers who facilitate the patients' improvement and well-being. Nowadays, home care depends on care networks that involve a variety of care actors, including informal caregivers (family members, friends, or neighbors), home helpers, and professional caregivers (nurses, physiotherapists, dieticians). This broader network of caregivers might also include pharmacists and technicians (Consolvo et al. 2004). In addition to people involved on an individual basis, we can see institutions involved in providing home care, like community care centers, call centers, and providers of social and technical services (Bratteteig and Wagner 2013).

Furthermore, the challenges of a growing ageing population and the increased needs of caring for chronic conditions drive the move towards technology-enabled care in the home and self-care across the developed world (Davis, Wagner, and Groves 1999; Imai, Jacobzone, and Lenain 2000; Chevreul et al. 2010). This move is characterized by decreasing levels of professional involvement and increasing emphasis on patients and their caregivers as essential participants, and on the home as a place for care (Fitzpatrick and Ellingsen 2013).

In the following, we review the literature investigating how to support cooperative work in the home care context.

We start with exploring the implication of having the home as a place for care, and then we explore the different forms of cooperation that are needed for the home care provision. Finally, we focus on the technologies used and developed to support the cooperation of actors involved in home care.

### **2.3.1 *The home as place for care***

Many researchers have been interested in the home of the patient as a place for conducting care work and its effect on the way care actors work and collaborate. The home of the patient, as an environment for care work, is difficult to modify; so, care actors have to negotiate with the patient and family members to achieve their work (Petraou 2007).

Thus, patient and family members have an active role in facilitating the care work. Patients manage their personal health information and collaborate with physicians and other caregivers. This is especially true for patients with chronic diseases (Bardram, Bossen, and Thomsen 2005; Mamykina et al. 2008; Chen 2011). However, studies show that prevalent norms and values play a role in how people engage in their healthcare, particularly at home (Palen and Aaløkke 2006; Piras and Zanutto 2010). For example, patients at hospitals concentrate on being sick; they have a passive role, and they could rely on health professionals to take care of them. In contrast patient at home have multiple roles (e.g. spouse, grandmother), they are engaged in day-to-day and social activities. While it is normal to be a patient in a hospital, a home is not commonly assumed to be a place for sick people. Thus, patients who want to continue their daily

life may want to minimize or discard the patient role. Furthermore, the home of the patient is not organized to support caring activities; thus, issues arise from sharing home with other family members, e.g. (Balaam et al. 2011).

### **2.3.2 Work and cooperation in home care**

Many studies explored the home care work as well as the actors involved in it (Rook 1987; Kahn 1993; Petrakou 2007; Lindley, Harper, and Sellen 2008; Christensen and Grönvall 2011; Bratteteig and Wagner 2013).

Some studies highlighted how the patient and family members might carry out care activities that we can qualify as work (Christensen and Grönvall 2011; Bratteteig and Wagner 2013), and how the activities done by the informal caregivers is complementary to the work of professional caregivers, particularly when caring for an elderly person (Christensen and Grönvall 2011). Thus, the collaboration between informal and professional caregivers contributes to the quality of care provided to the patient (Triantafillou et al. 2010). Informal and professional caregivers might adopt different attitudes toward taking care of the patient (Christensen and Grönvall 2011). Informal caregivers, and particularly family members, have a strong emotional investment in the care and well-being of their beloved ones. In contrast, professional caregivers tend to adopt an emotionally detached stance to protect their emotional health. Thus, the difference in the attitude might have an impact on the way care actors engage in the articulation work necessary for the care work (Christensen and Grönvall 2011).

Other studies focused on the mobility of care actors and its implication on their cooperation. In fact, the majority of home care workers are mobile and meet rarely, so it is difficult for them to achieve collaborative tasks like scheduling meetings, information distribution, information retrieval, short-term treatment coordination and long-term treatment planning (Pinelle and Gutwin 2002; Nilsson and Hertzum 2005). In fact, home care workers spend a little time in a shared office, which make the chance to have opportunistic collaboration rare (Bricon-Souf et al. 2005), and formal collaboration may be challenging due to schedule variability within the team (Pinelle and Gutwin 2002; Pinelle and Gutwin 2003; Nilsson and Hertzum 2005). Thus, some home care workers adopt a loosely coupling way of organizing collaboration to preserve their autonomy. In this mode of organization, workers minimize collaboration and interdependencies to deal with the unpredictability of the work setting (Olson and Teasley 1996; Grinter, Herbsleb, and Perry 1999). When they need to collaborate, workers attempt to initiate contact with others in ways that minimize the effort (B. Brown 2003). For example, home care workers prefer asynchronous communication as it allows them to overcome uncertainty about others' schedules, locations, and availabilities (Pinelle and Gutwin 2003; Bricon-Souf et al. 2005).

Another source of complexity stems from the need for adapting and changing caregiving activities dynamically to accommodate the evolution of the care recipient's condition (improved or deteriorated). While the organization in loosely coupling collaboration

offers a way to reduce the interdependencies and collaboration among distributed home care workers, the dynamic adaptation for the constantly evolving needs of the patient presents a challenge as caregivers need tight coordination (Nilsson and Hertzum 2005).

Some studies focused on the use of artifacts to facilitate collaboration between care actors involved in home care. Cooperation in home care setting is complex, because care actors are expected to coordinate within their organization (e.g. between work shifts) as well as across organizations. Thus, the workers are required to communicate and coordinate their activities across both their disciplines and their organisational boundaries (Petraou 2007; Petraou 2009).

To meet the challenge, the involved care actors might create tools and conventions to enable the collaboration between the variety of care actors. (e.g., SVOP binder (Petraou 2007), liaison notebook (Abou Amsha and Lewkowicz 2014)). In addition to disseminating formal information (related to patient status of health, e.g. administrated medications), artifacts are usually used also to support informal conversation required in a multidisciplinary cooperation like home care work (Westerberg 1999; Hardstone et al. 2004; Abou Amsha and Lewkowicz 2014). We can find similar results in the work done on the use of medical records in hospitals where health professional use post-its on the official medical record to support informal conversations (Fitzpatrick 2004).

### **2.3.3 Technologies to support collaboration in home care**

*Computer-based support for cooperative work can be provided by offering better communication facilities, providing improved monitoring and awareness possibilities to the actors, and by aiming at reducing the complexity of the coordination activities to be conducted by the involved actors. (Carstensen and Schmidt 1999, 620)*

In the following, we review technologies used and systems designed to enhance the cooperation between actors involved in the home care work. We can identify two main groups of efforts aiming at supporting cooperation in home care work; the first group focuses on enhancing the awareness through the use of monitoring technologies and the second on the use of integrated information systems.

#### **2.3.3.1 Monitoring technologies to enhance awareness**

Many studies implemented monitoring technologies to improve the awareness among 'care network' members (Consolvo et al. 2004; Abowd et al. 2006), and provide rich context information about the patient's home (Paganelli and Giuli 2007).

Telemonitoring systems generally include monitoring devices with web-based data sharing to enable health professional tracking the progress of the patient state of health. (Bardram, Bossen, and Thomsen 2005; Mamykina et al. 2008; Andersen et al. 2011). Some systems are based on sensors that gather information about the status of the patient to enhance the peace of mind of the informal caregivers (Mynatt et al. 2001;

Rowan and Mynatt 2005; Bossen et al. 2013). We can quote for instance the "Digital Family Portraits" system (Mynatt et al. 2001) that informs the informal caregivers about the status of their beloved ones through telemonitoring technology. The system provides icons around a picture frame in a remote family member's house that depicts different activities levels of the older person based on data from sensors implemented in the home.

Beyond the passive approach where the patient represents only a source of data that other care actors read and interpret, recent work offers to include the patient in the process of monitoring data interpretation. For example, in their work on cardiac telemonitoring, (Andersen et al. 2011) propose augmenting an implantable cardioverter-defibrillator (ICD) with a web-based application called myRecord to enable patients to provide missing socio-technical data and to collaborate with the physicians in interpreting their data.

### *2.3.3.2 Information sharing to enhance communication and coordination*

The advance of technologies has opened the possibilities for sharing clinical information across clinical settings boundaries. The electronic health record (EHR) represents one example of the major tools for healthcare professionals that help them both documenting and retrieving information concerning the patient's medical history (Blobel 2001); thus, the EHR comprises clinical data necessary for supporting the process of decision-making and cooperation between various health professionals (Reuss et al. 2004). However, designing a system that integrates information from the different EHRs is still a challenging issue (Hurlen, Skifjeld, and Andersen 1998).

Some researchers have proposed systems that allow sharing patient records among different care professionals, relatives of the patients and patients themselves (Hägglund et al. 2007).

Another way to support collaboration through information sharing is by enabling patients and informal caregivers to document the information related to the health status of the patient. The personal health records (PHR) used by patients to organize their health-related information, and to share it easily within their care network (Piras and Zanutto 2010). For example, Estrellita's system (Hayes et al. 2011) designed to support parents caring for their infants born prematurely; the system enables the parents to document and share health data of their child with professionals who, through message service, comment the data and answer the questions of the parents.

Another example is the CareCoor system (Bossen et al. 2013) developed to support cooperative work between relatives and home care workers around elderly persons. The system provides access to a shared view of the care tasks, and enable family members and home care workers to exchange messages pertaining to the care of a the patient as well as scheduling new care tasks.

Finally, some research focused on workflow systems to enhance the collaboration and the communication in home care; in their work (Lamine et al. 2014) propose for



instance an ontology-driven approach based on ontology matching between homecare domain models and semantic representation of Business Process Modeling Notations (BPMN) to help in the conception of workflows adequate to home care.

## 2.4 CONCLUSION

The literature provides elements on the basic characters of collaboration in a knotworking process. In (Table1) we present the issues we are focusing on to help us investigating and supporting the collaboration in knotworking process and how these issues been addressed in the CSCW literature. We also associate some examples of systems developed to support collaboration in home care context and which address aspects of the knotworking.

**Table1: Summary of literature review**

Characteristics of knotworking	Insights from the CSCW literature	
	Concepts	The case of collaboration in home care
<ul style="list-style-type: none"> <li>- The collaborative ensemble is not a priori defined and is constantly evolving</li> <li>- The work arrangements are not defined and not predictable</li> </ul>	<ul style="list-style-type: none"> <li>- Boundary objects</li> <li>- Coordination mechanisms</li> <li>- Common Information Space (CIS)</li> </ul>	<ul style="list-style-type: none"> <li>- Using monitoring to increase awareness of the patient's situation and adapt the care(Bardram, Bossen, and Thomsen 2005; Mamykina et al. 2008; Andersen et al. 2011)</li> <li>- Using electronic patient files (like EHR or PHR) to allow every stakeholders to take part in the communication around the patient (Hayes et al. 2011), (Reuss et al. 2004), (Hägglund et al. 2007), (Piras and Zanutto 2010).</li> <li>- Supporting the organization of care at home (Bossen et al. 2013)</li> </ul>
Collaboration occurs in episodes	-	-

Throughout the thesis, we will illustrate how investigating knotworking from a CSCW perspective can enhance the understanding of the concept and the ability to support it with technologies.

Moreover, by investigating knotworking, we contribute to the CSCW research by extending its focus to consider challenges that emerge due to implementing this innovative way of organizing work.

Finally, our case study contributes to the existing literature investigating collaboration in home care context. Compared to other studies, our work focuses on self-employed health professionals, who do not belong to any organization and do not follow any pre-defined protocol nor use a common information system. Their collective organization around the patient is self-regulated, and compared to the classical practices of care workers (at least in France), they value equally the work of all of them and there is no hierarchy between doctors and other participants.

### **3 THE CASE STUDY**

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In this chapter, we describe the "e-maison médicale" association, which groups self-employed health professionals who cooperate to provide home care for patients with complex situations in the city of Troyes (N-E France) and its agglomerations. We observed the collaborative practices of the members of this association and we argue that the way they are working represents an example of knotworking. This chapter is divided into four sections; the first one presents an overview of the context in which the e-maison médicale association was created as well as a brief presentation of its work, the second one details the method we used to investigate the collaborative practices taking place to take care of patients at home, the third one reports our results from data analysis, and finally, the fourth one discusses these results.

### **3.1 CONTEXT**

In this section, we provide an overview of home care in France. First, we describe the current state of the French health system, as well as the main issues challenging its current organization. We list a few of the major reforms of the health system aiming at developing collaboration between different care providers to enhance the quality of care. Then, we introduce the concept of "Domomédecine", which takes an innovative approach to health care delivery by giving home care a central role. After that, we focus on the current context of home care, how the care is provided and what are the main actors. Finally, we present "e-maison médicale", an innovative way of organizing home care delivery in a collaborative way in this context.

#### **3.1.1 French Healthcare System: Challenges and reforms**

The French healthcare system performs very well in satisfying the expectations of the population, providing high-quality services, with freedom of choice and no waiting lists for treatment (Rodwin 2003). However, the health system is challenged by socioeconomic disparities and geographic inequalities in the density of healthcare professionals. Moreover, the rising expenditure and consequent deficits in statutory health insurance, along with a slowing economy, and unemployment rising is a major concern (Chevreul et al. 2010).

The cost-containment policies aiming at limiting supply and restricting coverage have been hindered by public dissatisfaction and ardent opposition of the medical professions that are used to have independent medical practice (Imai, Jacobzone, and Lenain 2000).

Furthermore, the French health system has a very decentralized nature, which is illustrated in the separation between health and social services, institutional and community-based care services, private, non-profit and public services, and finally between the various payment systems (Henrard 2002). The fragmentation is reflected in the management of the healthcare system by different institutions, even on the national level, there are two ministries (the ministry of health and the ministry of solidarity) and two insurance systems (health and retirement pension) are responsible

for elderly people with chronic conditions. In this context no single institution is able to determine, for example, a gerontology policy. This decentralized nature may explain why the French healthcare system is so difficult to reform (Trouvé et al. 2010).

As in many developed countries, France has an increasing number of elderly people suffering from chronic conditions. This demographic shift, associated with growing healthcare needs, challenge the re-organization of long-term care (Robine and Michel 2004).

The French health system, which is mainly focused on acute care, has been the subject to many reforms to cope with the long term care challenge (Somme and de Stampa 2011). In the following, we are first presenting a few of the influential reforms that affected the modes of cooperation in the French health care system. Then, we highlight the main actors of long-term care in France.

Since 2006, the reform of the Health Insurance encourages the creation of "coordinated care pathway<sup>1</sup>" in which the general practitioner (GP) occupies a pivotal role. Chosen by the patient, the general practitioner performs primary care and if necessary directs the patient to specialty care. The preamble to the 2006 convention stated that, to achieve his/her mission, the GP relies on a network of health professionals that s/he can ask on the various aspects of the diagnostic or therapeutic treatment of his/her patient. However, the coordination between the GP and other self-employed health professionals or health care facilities (e.g. hospitals) has not been precisely established by the reform. This highlights the fact that coordination is most often the result of personal networks.

In 2010, the reform 'Hospital, Patients, Health Territories,' has created a unique agency at the regional level (ARS<sup>2</sup>) that unites multiple institutions like the regional institutions for hospitals (ARH<sup>3</sup>) and the regional health insurance providers (URCAM<sup>4</sup> and CRAM<sup>5</sup>). The objective of all the ARS is to manage the overall delivery of care in close collaboration with the social services sector.

The reform has introduced a primary care offer<sup>6</sup>, which combines multiple health professionals, in cooperation, if necessary, with healthcare facilities and social and

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<sup>1</sup> "Le parcours de soins coordonnés" consiste à confier au médecin traitant la coordination des consultations et soins pour le suivi médical de l'assuré. Le respect du parcours des soins conditionne la prise en charge des dépenses de santé. A défaut, l'assuré supporte des pénalités financières.

<sup>2</sup> Agence Régionale de Santé

<sup>3</sup> Agence Régional d'Hospitalisation

<sup>4</sup> Union Régionale des Caisses d'Assurance Maladie

<sup>5</sup> Caisse Régionale d'Assurance maladie

<sup>6</sup> Article L. 1411-11 of the Public Health Code. Primary care offer includes prevention, screening, diagnosis, treatment and monitoring of patients; dispensing and administration of medicines and pharmaceutical advice; orientation in the care system and the medical-social sector; health education.

medico-social service providers. The health professionals can engage, at their initiative, in a cooperative approach with the objective of organizing the exchange of information or reorganize their modes of intervention in caring for the patient.

However, the health professionals have to submit the cooperation agreement or protocol to the Regional Health Agency for approval. The cooperative protocol proposition specifies the purpose and the nature of the cooperation including disciplines or pathologies, place and the scope of intervention of health professionals. Once approved by both the Regional Health Agency (ARS) and the High Authority of Health (HAS), the cooperation protocol can be implemented on the regional level.

In some cases, the High Authority of Health (“Haute Autorité de la Santé”, HAS) might extend the cooperation protocol throughout the national territory. Expanded cooperation protocols are integrated into the initial training or continuing professional development of health professionals.<sup>7</sup> For long-term social aspects, the general councils at the local level play a significant role in managing the care services in term of agreements, and prices. These councils provide for instance social fund allocation for high chronic impairments (“Allocation Personnalisée Autonomie” - APA). Another actor in social services is the retirement insurance that might support the implementation of home assistance services for people with low levels of impairment.

In summary, the French healthcare system is decentralized, as it is governed partially by regions and “departments”<sup>8</sup> as well as few links between social services and health care. Currently, the healthcare system is moving toward a more integrated care system to face the actual socioeconomic challenge (Somme and de Stampa 2011). However, reaching the aimed integrated health care system in this challenging situation requires innovation in the health care delivery. In the next section we present one innovative vision of a health care system organized around the patient and with the patient.

### **3.1.2 Home care in France: from Ambulatory medicine to domomedicine**

Ambulatory care history goes back to the late 18th century when the Duke de la Rochefoucauld-Liancourt suggested that the Constituent Assembly should "develop the emergency at home rather than in clinics."

In 1956, a service of the Institute Gustave Roussy (IGR) in Villejuif, organized "the continuity of home care" by the general practitioners. In the late fifties, hospitals such as Assistance Publique-Hôpitaux de Paris (AP-HP) and para-public structures in particular IGR,, developed schemes of medical treatment emphasizing on maintaining the patient

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<sup>7</sup> (LOI N° 2009-879 Du 21 Juillet 2009 Portant Réforme de L'hôpital et Relative Aux Patients, à La Santé et Aux Territoires - Article 51 2009, 51)

<sup>8</sup> In the administrative division of France, the “department” is one of the three levels of government below the national level, between the region and the commune (city or group of small cities and villages). There are 13 regions and 96 departments in metropolitan France. A department is administered by an elected body called a departmental council (conseil départemental).

at home and on the role of the patient's family in providing efficient treatment (Lévi and Saguez 2008). These initiatives concern diseases such as myocardial infarction, arthritis or leukemia. They are designed to delay, avoid, defer or shorten hospitalization, and extend home care (Pierre and Soutoul 1989).

According to the report of the French Academy of Technologies in 2008, the emergence of these structures as an alternative to hospitalization, intended to answer: First, patients' demand of a medical care that minimizes rupture of family social or professional ties; second, a shortage of hospital beds and the objective to reduce hospital overload; finally, the need for savings in the care consumption (Lévi and Saguez 2008).

Recently, more patients prefer to avoid hospitalization if they can have ambulatory medicine that offers adequate medical and health care of a comparable quality to the one provided in clinical settings. Besides, there is a growing number of patients needing more involvement in the decision-making process regarding their health.

Besides, technology advances and their adaptation for the medical domain enabled the development of ambulatory medicine. Nowadays, it is possible, for example, to record biological functions over prolonged periods and analyze the collected information and thus enable administering complex treatments, outside clinical settings.

These technological and societal developments along with the economic and logistic challenges of long-term care motivated the French academy of technologies in 2008 to propose a new health system with the patient in the center of the health care organization and where the home of the patient is the place where the care actions occur. This health system was named "domomédecine" by the French academy of technologies.

*"[Domomédecine] consists in a health care system which allows the patient to remain at home or to continue his or her normal activities while receiving medical assistance and healthcare with similar high standards of quality and quantity as those available at the hospital". (Lévi and Saguez 2008, page15).*

In this vision of the healthcare system, the best framework for certain care actions is the patient at home and the hospital becomes a stakeholder in the health system and not the center of it anymore. Domomedecine proposes moving the care to the patient at home to answer socio-economic challenges. However, its implementation requires a real change in the current practices of home care delivery.

The implementation of domomedecine relies on the advanced technologies and requires coordination between the different care actors (patients, doctors, nurses and auxiliary medical personnel, etc.). Thus, information system supporting this health care system must deal with large amounts of information being passed between various users who not always belong to the same organizations.

This thesis is conducted in the context a larger French research project called PiCADO, funded by the interministerial fund for innovation. Its objective is to design, develop,

test, and evaluate the first operational system of domomedecine. Thus, our case study, we believe, will offer us the necessary insights to first, understand the current practices of home care delivery and second to design adequate technologies supporting collaboration in this context.

In order to explore the current context of home care before introducing our case, in the next section we review the existing offers of home care services in the French context.

### **3.1.3 Current state of Home care delivery in France**

Home care services are mainly provided by self-employed health professionals (Chevreul et al. 2010). While this situation fosters the personalization of care (patients are being treated by their usual health professionals), the patients, and their families still have to the charge of transmitting information from one health professional to another, and of organizing the visits of the different health professionals.

For more severe situations in which heavy medication, sophisticated medical equipment, and close monitoring are needed, “hospital at home” service (“Hospitalisation à Domicile” – HAD) is offered. In this case, care professionals are employees; they are organized in teams and use a binder to trace all their actions.

Only a hospital doctor or a general physician can refer a person to HAD. The agreement of the general physician is necessary because s/he take the medical care responsibility with the HAD. Usually, this kind of service follows a hospitalization (a surgery or chemotherapy for instance). Thus, the “hospital at home” team usually reports to the hospital.

Before admission, the HAD coordination team visits the home of the patient to assess the feasibility of the care project and to determine the material conditions and the skills required. The coordination team members create the care plan that should be validated by the coordinator (normally a general practitioner). The person receiving care and his/her entourage are informed about intervention conditions (care nature, care schedules, administrated treatments, prevention and risk management). Wherever possible, the organization of care takes into consideration the wishes and personal constraints of patients and their families.

For the realization of the care plan, the procedure of the HAD differs according to the establishments. While the establishment employs the staffs of the coordinating team, the professionals providing home care (ex. nurses, physiotherapists.) can be self-employed, and even already known to the person being cared for. In this case the liberal professionals have to sign a convention with the HAD. However, The HAD staff treats the patient only for the conditions detailed in the care plan. If patients have any other medical problems, they will continue to be treated by their general practitioner, district nurse or other hospital departments as appropriate.

Depending on the case, medicine can be delivered through HAD pharmacy (as in a hospital) or by a pharmacist in town. For emergencies, the establishment of HAD makes



available to the person and his entourage an alert protocol. At minimum, the HAD provides immediate telephone access to a nurse 24 hours a day, 7 days a week. Some HAD establishments offer the possibility of a home nurse night shift in the patient house.

Here, it is worth noting that between the “hospital at home” where patients need close monitoring, and the isolated practices of self-employed health professionals, there is a gap in home care services. For example, a patient who suffers from a chronic condition requires having a close eye on the progress of his condition to avoid unnecessary acute accidents. In this case, the situation of the patient is not yet critical to send them to a hospital or to ask for a hospital at home service. However, the self-employed health professionals working in isolation would not be able to have a comprehensive vision of the patient’s condition without communicating and they cannot organize the necessary care without coordinating their work.

Recently, more and more innovative initiatives aiming at organizing the efforts of self-employed care professionals around the patient at home have emerged. This move is encouraged by the reforms of the healthcare system and the need for new offers of home care services. In the next section, we present the case of the e-maison médicale association, which represents one of these few successful initiatives for promoting collaboration in the domain of home care in France.

### **3.1.4 *E-maison médicale – a local initiative for home care***

The e-maison médicale association gathers different self-employed health workers and professional caregivers, located in Troyes agglomeration (N-E of France). They aim at promoting a collaborative approach to home care delivery.

The association was created in 2011. Currently, the association has about eighty members including various medical professions: professional caregivers, physiotherapists, biologists, physicians, pharmacists, nurses, and home helpers.

Health professionals providing home care do not have any shared responsibility for the patient’s situation. Professionals collaborate and exchange experiences to provide a better quality of care. However, the lack of regulation makes many health professionals consider collaboration as doing extra work for coordinating and communicating without getting an appropriate reward.

The collective care at home becomes necessary when patients have complicated medical conditions that require the intervention of multiple care actors. In other words, without the collective care at home, patients would need to be admitted to care settings or request a hospital at home service.

Members of e-maison médicale continue to provide simple home care services for their patients, but for those with complicated medical conditions, they cooperate with other care actors to keep the patient safe at home.

#### *3.1.4.1 Functioning*

A patient can benefit from this collaborative care if his physician (or any other care professional) is a member of the e-maison médicale association.

Depending on each patient's needs, the care ensemble might include nurses, dieticians, pharmacists, specialists, physicians, mental health services and home helpers. Patients and their families are a fundamental part of the care group. Together, the members of the group participate in creating a "care plan" that includes the patient's personal goals.

The association aims at motivating patients' current health partners to collaborate. In fact, as we mentioned in section (3.1.1), healthcare professionals in the primary sector are attached to their independent work practices. The association does not standardize the work practices but try to combine different skills to improve the quality of home care delivery.

#### *3.1.4.2 Illustration*

Mr. NG is a patient suffering from Alzheimer's disease; living with his wife, Mrs. NG. She did her best to keep caring for her husband, but the situation is getting more difficult as patient's status drops. Also, Mr. NG is suffering from pulmonary problems that make it harder to keep him safe at home.

Mrs. NG started to search for help, but the existing solutions were not compatible with her promise to stay with her husband. Mrs. NG is not able anymore to provide needed treatment and care, a fact that increases the anxiety of the separation.

The family's doctor (a member of e-maison médicale) suggests putting in place a group of care professionals to help in day care, and for the administration of the different treatments. The care group includes a nurse, a home helper, a physiotherapist, and the physician. Depending on the needs, the care professionals come several times per week or day. Mrs. NG can rely on the care professionals 24/7, and the pharmacy delivers the necessary medical devices and medications, to ease the charge of the wife.

The care actors use a paper-based notebook to keep everybody informed of the patient's situation. This notebook stays with the patient, and all care actors, including Mrs. NG, write their observations in it. The liaison notebook keeps a log of the care actors' actions, the questions care actors have, or the requests they formulate to other care actors. Sometimes care actors put in the notebook suggestions about the style of documentation (e.g. writing patient's temperature in the margin) or notifications (e.g. need to renew a prescription). The wife uses the notebook to document the patient's medical appointments, his changing moods and health status.

The care group organizes meetings in the patient's home when needed. The care group works with little resources but succeeds in keeping Mr. NG safe at home, and Mrs. NG does not spend her time calling for appointments.

In this context, we are interested in exploring how the care actors collaborate to provide care and preserve the quality of life of their patients. Also, we are investigating the issues that hinder their collaboration and what to consider when designing a technological support for this collaboration context.

In fact, even when the collective management of the patient's condition is satisfactory for the patient and their entourage, the care actors are encountering challenging issues like the absence of shared responsibility, and the difficulty of including new members, and the relation between the home care team and other providers of health care. We make the hypothesis that information and communication technology (ICT) could offer support to overcome challenges raised by this collective approach of home care.

## **3.2 METHOD**

### **3.2.1 Data collection**

#### *3.2.1.1 Fieldwork*

We used ethnographic methods (Randall, Harper, and Rouncefield 2007), combining interviews observation, and discussion sessions. Besides, we made two design workshops where we used mock-ups and scenarios to assess the implications for design that emerged from our findings.

We conducted a study over a period of fifteen months. Inspired by the grounded theory approach (Glaser and Strauss 1967), the results of our data analysis guided our further data collection. We focused on collaborative practices of the home care actors and the used artifacts.

As a starting point, we conducted semi-structured interviews with nine care actors providing home care services (four physicians, two gerontologists, two speech therapists and a registered nurse). The interview duration lasted between 40 and 50 minutes, the protocol of the interview included questions like (a) how do they provide home care? (b) What sort of information do they share with other health professionals? (c) What kind of coordination tools do they use? (d) What is the role of the collaboration in providing quality home care?

Although care actors considered collaborating with each other as positive for the quality of care, most of the care actors were still working on a solo basis. However, some care actors described their communication with each other and their coordination of work for particular patients. In our second round of data collection, we chose to focus on the work of the e-maison medicale association that was especially created to motivate collaboration between different home care actors gathered around a patient.

We organized a discussion session with five members of the association, participants included a physician, a registered nurse (co-founders of the e-maison medicale), a physiotherapist and two home helpers. We recorded the discussion and noted down

remarks. This discussion session lasted three hours and motivated us to conduct an observation to see how actors coordinate their work in situ.

Hence, we followed the registered nurse (one of the two founders of the association) for three days (15 hours total). We visited 20 patients' homes per day. We took photos and noted down information<sup>9</sup>. During and after each visit, we asked questions to the various care actors (mainly home helpers and family caregivers).

This observation gave us a useful insight of the care practices of e-maison médicale members and highlighted the important role of the "liaison notebook" in the patient's home (Abou Amsha and Lewkowicz 2014). The notebook provides an asynchronous way of sharing information and communicating among the different people involved in the care of the patient.

To go further, we organized a new discussion session with the founders of the network (a registered nurse and a physician), focusing on how the notebooks support the collaboration between the care actors. The session lasted for three hours; we took notes and photos of the different liaison notebooks, we recorded the meeting and analyzed the transcript. We also collected a sample of eleven liaison notebooks (Table 2).

Patient	Number of notebooks	Pages	Period
SS	1	50	11/2011-06/2014
MD	1	84	08/2011-06/2014
LD	1	100	11/2011-05/2014
SG	8	340	2007-2014

**Table 2: The sample of liaison notebooks**

During the three years of our research work, we also joined the monthly meeting of the association, where members discuss their practices and work on extending their logic of work to include more members. We were also involved in different occasions in some manifestations concerning the e-maison médicale, like the presentation of their work to a new public, or their collaboration meeting with the hospital of Troyes. This involvement, we believe, contributed to our understanding of their practices and the challenges they are facing.

Table 3 provides a summary of all the techniques used to collect and analyze fieldwork data.

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<sup>9</sup> Our main focus was the work of the nurse, and before taking photos we took the permission of the patients or their family's members.

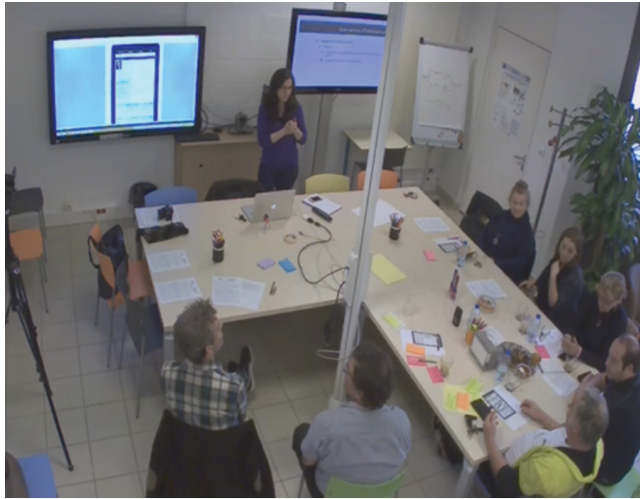
	<b>People involved</b>	<b>Period</b>	<b>Comments</b>
<b>2013</b>			
<b>Interviews</b>	9	16 hours	Interviewees were four physicians, two gerontologists, two speech therapist and a registered nurse
<b>Discussion session</b>	5	3 hours	Participants were a physician, a registered nurse (the two co-founders of the e-maison médicale), a physiotherapist and two home helpers
<b>Observation</b>	1	15 hours	We followed a registered nurse and visited 20 patients' homes
<b>2014</b>			
<b>Working session</b>	2	3 hours	Focusing on the liaison notebook with the physician, and the registered nurse (co-founders of the e-maison médicale)
<b>Document analysis</b>	4	2 months	We collected eleven liaison notebooks belonging to four different patients
<b>2015</b>			
<b>First design workshop</b>		4.5 hours	Participants were three home-helpers, a registered nurse, a physiotherapist and physician
<b>Second design workshop</b>		4 hours	Participants were three home helpers, a registered nurse, a physician, and a specialist.

**Table 3: list of techniques of collecting and analyzing data**

### 3.2.1.2 Design

Together with the home care actors, we designed an application to support their collaborative practices. The objective was to assess the implications for design stemming from our results detailed in the section (3.3). For so doing, we organized two design workshops with different home care actors who were members of the e-maison médicale association.

The first design workshop (Figure 1), lasted four hours and a half, and we had six participants: three home-helpers, a registered nurse, a physiotherapist and physician. We used mock-ups and scenarios. The three scenarios addressed the collaboration of regular care actors and the participation of one-time care actors in the collective management of patients at home. Participants had printed copies of the mockup, and they commented our propositions and suggested new ideas. At the end of the workshop, all the ideas were arranged on a board (Figure 2). We filmed the workshop, took photos and wrote notes.



**Figure 1: First design workshop with home care actors**



**Figure 2: Feedback from home care actors**

The second workshop (Figure 3) lasted four hours, and we had six participants: three home helpers, a registered nurse, a physician, and a specialist (all participants, except the specialist, have participated in the first design workshop). We presented a prototype of the application with use scenarios. Participants worked with the prototype (Figure 4) and gave us valuable feedback. We were three researchers working with participants, taking notes, and photos.



**Figure 3: Second design workshop with home care actors**



**Figure 4: Participant working on the prototype**

### 3.2.2 Data Analysis approach

Inspired by the grounded theory approach to qualitative analysis (Corbin and Strauss 1990), we used open coding and analyzed the data collected from our different sources (interviews, observation notes, discussion sessions)(Figure 5).

We iteratively coded the data; it took us three rounds of coding. The coding rounds were conducted by the same researcher but the resulted codes were discussed with a second researcher.

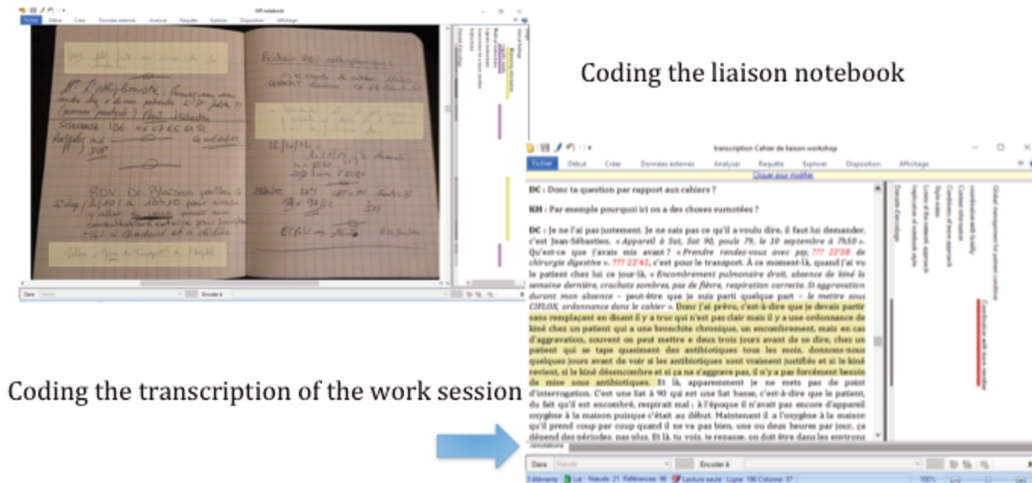


Figure 5: Coding process

In the first round (Figure 6), we were looking at the collaborative practices, we were coding information like the kind of collaboration strategies, and we defined codes like “acting together” or “asynchronous coordination”. We also coded the different kinds of information the people were sharing, with codes like “medical instructions”, “clinical finding” or “logistic needs”.

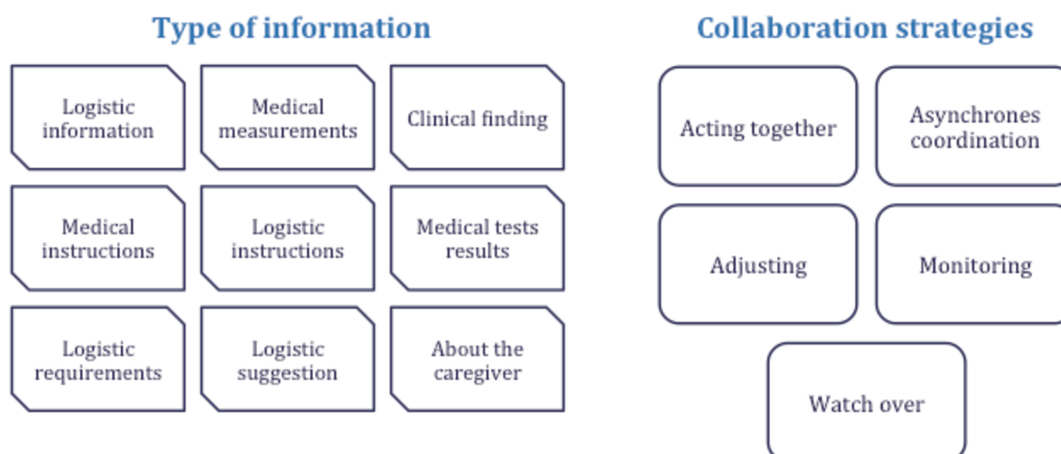
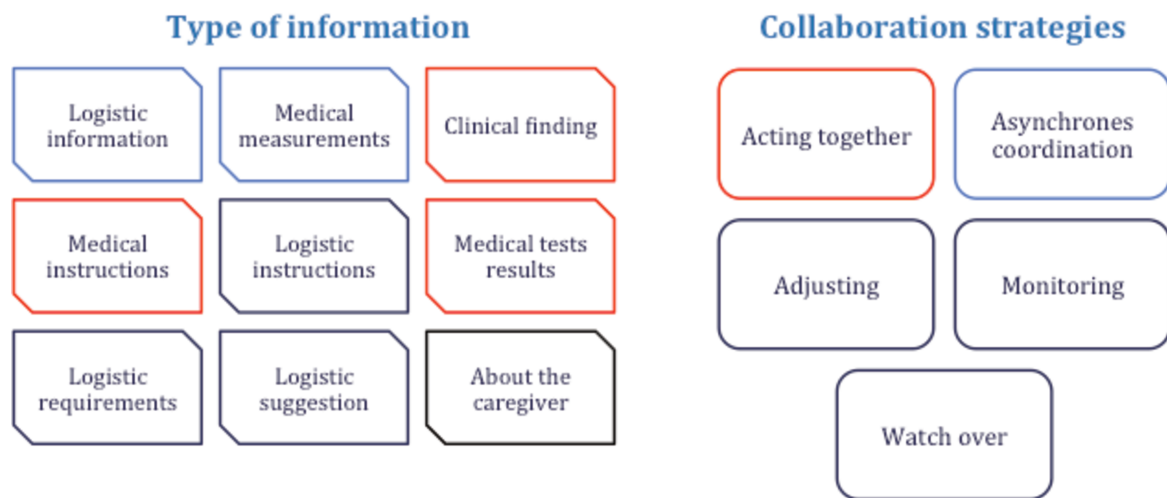


Figure 6: Example of the codes used in the first round of coding

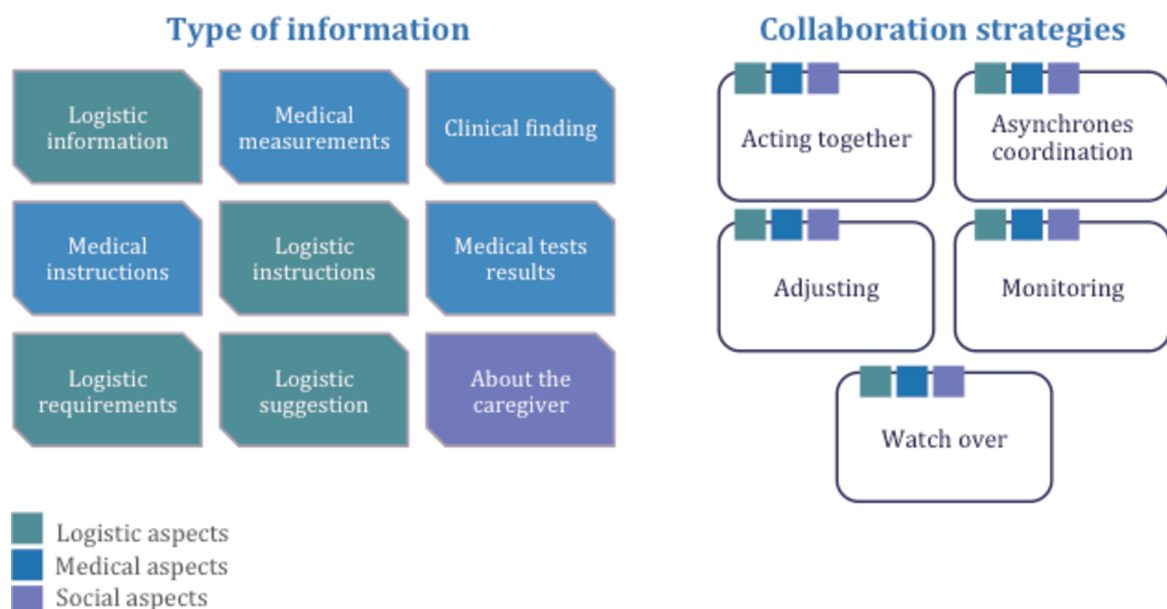
In the second round (Figure 7), we identified a relationship between the collaborative practices adopted by the care actors, and the kind of information they were sharing,

thus we coded different situations where we saw a pattern of practice-information structure: e.g. “treating an emergency”, “modifying care plan”, or “solving a problem”.



**Figure 7: Example of the identified relationships between practice and types of information (in red) in the second round of coding**

In the third and final round of coding (Figure 8), we identified a second level of classification related to different dimensions of the management of the conditions of the patient: “medical”, “logistic” and “social”. This classification highlighted how care issues emerge, and how these issues that might span multiple dimensions are treated collectively.



**Figure 8: Example of the results in the third round of coding**



### 3.3 RESULTS

#### 3.3.1 *The complexity of home care*

Obviously, managing the care of the patient at home differs from caring for the patient in a hospital. The home of the patient undertakes modifications in the place and lifestyle to enable caring for the patient safely. Receiving care at home is not only conditioned by the capacity of providing medical care at home, but also by the ability of the home of the patient (place and people) to afford the charge of care activities. The case of Mr. DR provides some insights about the complexity of providing home care.

#### **Illustration: the case of Mr. DR.**

Mr. DR is 89 years old, and he has been suffering from the Alzheimer's disease for ten years. During this period, the disease has evolved, and Mr. DR occasionally has behavior disorders (he becomes aggressive). Mrs. DR, who is 80 years old, is the main caregiver of her husband.

Last year, the patient's situation worsened, and now he cannot walk anymore. Normally, the wife organizes her husband's medical appointments with the physician, the specialist (the patient has heart issues), but now she relies more and more on home services. Currently, two home helpers come in the morning to do the wash and to place Mr. DR in the wheelchair, and they come back, in the evening, to put him back to bed. The physician visits the patient at home. The couple gave up going out even for visiting the cardiologist.

*Mrs. DR (wife): "It is difficult; even the simplest activity needs many preparations... In addition to, we have no family here to help us".*

In France, as we explained before, self-employed care actors provide the majority of home care services, and the patient or the patient's family has the freedom to choose their care actors. However, this means that the patient or the patient's family deals with all the administrative formalities and organizes the visits of the different care actors.

Thus, organizing the home care for the Mr. DR is still the responsibility of his wife. She has to be available all the time for the different visits of all care actors.

*Mrs. DR (wife): I understand that health professionals have a lot to address... but what about me? They do not respect their appointments [talking about home helpers], and we have to address hours of delay. In the beginning, I was telephoning and asking them to respect the timing, but now, I am just tired".*

Home-helpers punctuality is essential for Mrs. DR as she is not able to help her husband starting his day. Besides, the delay complicates the work of the nurse who puts the patient on a drip (perfusion), after the morning wash. In fact, home-helpers remove the drip, and return it after the morning wash, but not always in the right way.

The couple has a contract with an association for the home helpers services. Though the association provides constant care, i.e. there is always someone to help the couple, but the home helpers doing the work are continually changing and vary in competence and experience.

*Mr. DR (wife): "Each time, we have different pairs. Those that you saw today won't return for two weeks [referring to the home helpers]. Each time, I have to explain the drip and watch their work carefully to avoid problems. I thought that they have training for doing this work, but it is not always the case".*

Indeed, meeting different home-helpers each time creates tension with the family and prevents home helpers to be aware of the patient's situation.

*Mrs. DR (wife): "Once, I left my husband's room. They [referring to the home helpers] closed the door behind me. When I returned, they said to me, 'We do not need you here; we will call you when we need something.' So I said to her, 'I will stay with my husband'. After all, this is my home..."*

The situation of Mrs. DR is not unique, as expressed by one home-helper (Mrs. JK).

*Mrs. JK (home-helper): "You know, I can imagine it is not easy for the family. I saw my mother taking care of my grandfather... However, we [home helpers] have to stick to the schedule; we have to be fast and finish a list of tasks. It is not the best system, but we are providing the necessary care for our patients".*

The various care actors rarely communicate. Looking at the kitchen table of Mrs. DR, we can see different notebooks, one for tracing the home helpers activities, another for the physician and the nurse. Care actors write in their own notebook when they notice something unusual like marks on the skins or inflammation. Also, they might discuss it with the wife who transmits the information to other care actors.

Despite the challenging situation, Mrs. DR is not considering placing the patient in care setting. In the case of Mr. DR, the medical care at home is possible, even with the complication of his situation, i.e. him not being able to walk anymore. However, this model is reaching its limits as Mrs. DR is starting to get tired.

To create a more sustainable model for home care, the members of e-maison médicale extend their objectives beyond medical care to include maintaining the quality of life of patients and their families.

In the following, we present how this model takes place; first we present the "liaison notebook" as a coordinative artifact. Then, we show how issues spanning the medical, logistic and social dimensions challenge the provision of home care. Finally, we describe how care actors experience different rhythms of collaboration to handle emerging issues.

### 3.3.2 The liaison notebook as a coordinative artifact

Home care actors work mainly asynchronously; thus, the liaison notebook offers them a way to communicate about the situation of the patient. In the following, we will show the different types of liaison notebooks that we have observed, and we will illustrate the central role of these notebooks in the collaborative practices among the care actors.

The practice of documenting information about the patient varies according to the conditions of the patients. The patients who suffer from chronic diseases, like diabetes, need more precise monitoring and therefore have specific notebooks designed for this kind of reporting (Figure 9). In these notebooks, a care actor can easily indicate the level of sugar in the blood and the doses of insulin injected. Structured documentation assists care actors in prescribing and modifying the medications. Care actors might complete numbered values with comments. For example, a family caregiver comments on the relatively high-level blood sugar, explaining that the patient was assisting a party, and he ate a dessert (Figure 6). Care actors might also exchange messages discussing the numbers, for example, a nurse writes a message for the physician asking about the medication and the physician answers with a message during the patient consultation two days after (Figure 5).

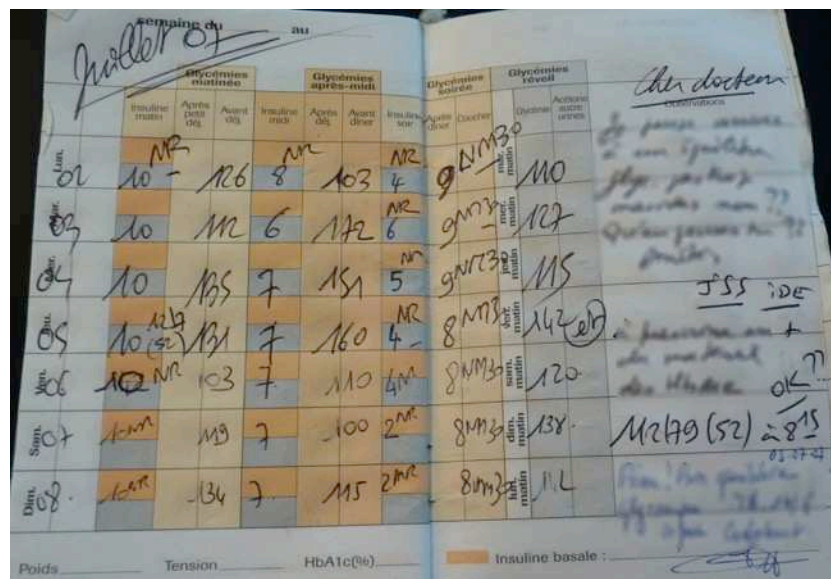


Figure 9: Diabetic diary

Date	Glyc	INS	CORT	TA	Poids	H°	Poids	T°
Sa. 06/04	101	0	6mg					
-	138	6	0	M6/64		80	37 <sup>08</sup>	SAT=98
-	123	0	0					
D. 4	106	0	6mg					
-	124	6	0					non annuelle
-	176	0	0					a mangé Tarte glace br chaude

Figure 10: Commenting values in a diabetic diary

Some liaison notebooks might be less structured, and according to the evolution of the patient's conditions, structured medical information coexists with freestyle messages. Figure 11 is an example of how the values that are controlled changed after the physician consultation to monitor some physiological values.

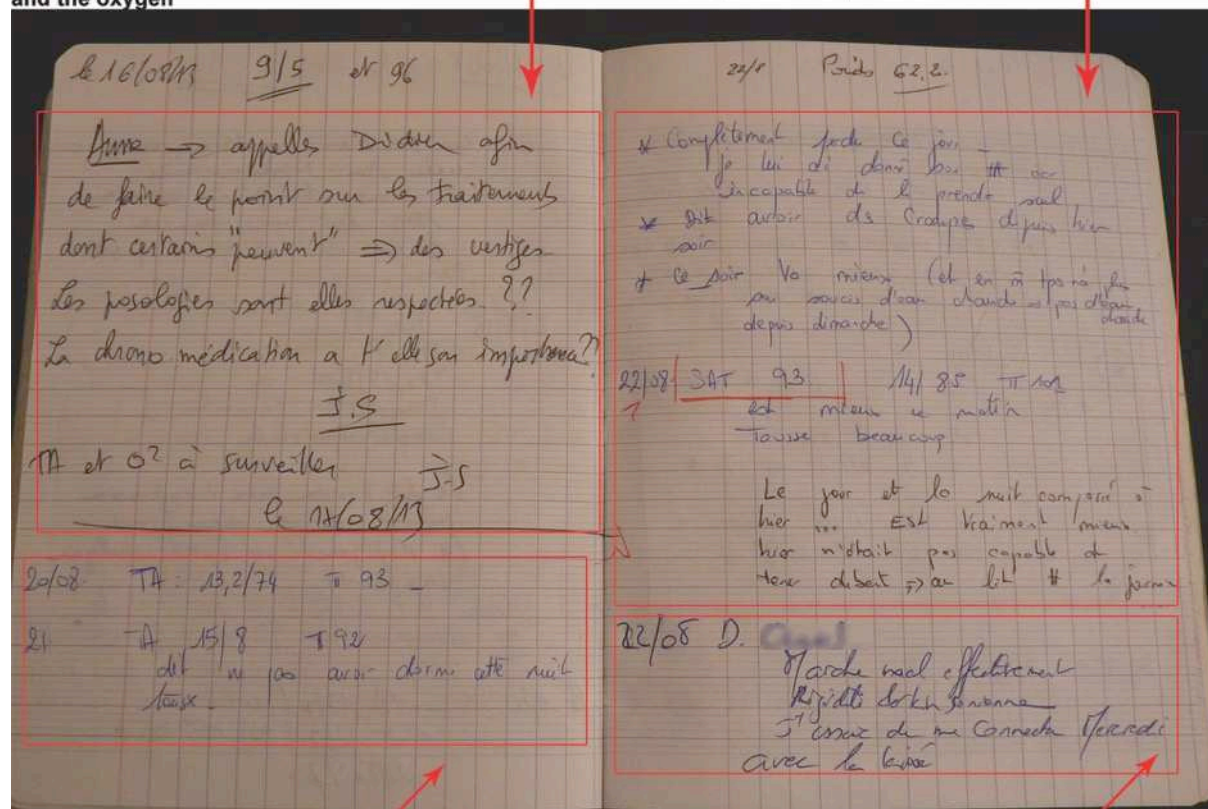
date	Température	urine	observations
16/11	matin: 37° soir: 37°		manque à la pharmacie mesure sol. ster, après contact
18/11	matin: 36° soir: 37°	150 cl	achat sucre physiologique + contre constipation: Normacol
20/11	matin: 37° soir: 36°	160 cl	lavement - après application de collyre - selles évacuées -
21/11	matin: 36° soir: 37°	200 cl	19/11 - pas de lavage de sonde avec la seringue, infirmière pas équilibrée
22/11	matin: 36° soir: 37°	220 cl	
<p>17/11 A priori toujours constipé - protocole 7 dr TA = 90/60 n = 65 Voir avec célestis pour prise en charge rapide du protéine de sonde urinaire Lactoscan = 1/4 - 1/4 - 1/4 - 1 Dossier A.S.A pour Auxiliaire de vie</p>			<p>Monitoring the patient's temperature and urine output + Narrative observations Physician note commenting the written information and asking to extend the monitoring</p>
22/11	22h00, et bien	évacue des selles, assez importantes "constipées" - (moules) -	
23/11	Temp. matin: 36° soir: 36° Temp. M. bras	200 cl	pesé, 66 kg a perdu 14 kg en environ 16 mois
			<p>Monitoring the patient's temperature and urine output + patient's weight</p>

Figure 11: Semi-structured monitoring

Finally, some liaison notebooks represent a record of exchanged messages in a freestyle way. A message might include a mix of physiological constants, clinical findings and remarks about the patient state of health. Thus, this style of documentation results in an ongoing, asynchronous, conversation between the care actors about the patient's situation (Figure 8).

Message for the secondary nurse asking her to call the physician and to monitor the blood pressure (TA) and the oxygen

The secondary nurse documents her observations and patient's impressions



The secondary nurse starts the monitoring

The physician confirms the secondary nurse observations and relates that he discussed this with the physiotherapist

Figure 12: Freestyle monitoring

Most of the liaison notebooks we have observed include information about who are the care actors working with the patient; usually there is a list of their names and contact information in the first page. This enables new care actors, or one-time care actors to contact the current care actors if they need further information about the situation of the patient and his/her current care plan. We might also find in some of the notebooks a page describing elements of the patient's medical history, but sharing this kind of information is still problematic because not all of the care actors officially have the right to read the patient's medical information (to ensure medical secret).

All liaison notebooks accommodate comments related to the management of the patient's care plan without being, in a strict sense, part of the medical information. This might be explained, we believe, by the need of organizing other aspects of care management in order to keep the patient safe at home. We develop in the next section the different aspects of care addressed by the care actors.

### 3.3.3 Addressing the Multiple Dimensions of Home Care

Our empirical study highlights that providing “quality home care” requires dealing with issues beyond the medical scope. When creating a care plan, the care actors handle the medical conditions of the patients, as well as their socio-economic situation, and even the home configuration. Indeed, they take into consideration whether the patients have any family caregiver, or whether they receive any financial and material support, or if they have enough room for medical equipment. Through our data analysis, we identified issues related to three facets of care: medical, social, and logistical issues.

#### 3.3.3.1 Medical Issues

To keep the patient safe at home, care actors are challenged everyday by medical issues; care actors collaborate to anticipate emergencies and to deal with problems properly.

Medical challenges include keeping a patient stable, handling the potential secondary effects of the medication, and handling accidents that worsen the patient's condition. To manage the daily medical decisions, care actors rely on the vigilance of each other. Patients with chronic diseases are an example where monitoring plays a significant role.

*JSS (nurse): “I have to look at what he ate or else I will give him an inadequate insulin dose, and he risks having hypoglycemia [decreased blood sugar concentration]... In his case, he [the patient] has memory problems, so I can count on the home helper who keeps a record of meals. In my turn, I write in the notebook the insulin doses and the blood glucose measures. The physician then can decide to maintain or modify the treatment based on this documentation.”*

The different care actors meet rarely, and the absence of a shared history of the patient might affect the patient safety.

*JSS (nurse): “I think that we are largely disrupted by a lack of written follow-up. When you have nothing to read, one is bothered, especially in monitoring like this [referring to the case of patient Mr. LD, mentioned later]. We are monitoring the risk of effects related to the administration of a corticosteroid and observing the couple that is aging”.*

Unlike in clinical settings, home care actors lack available logistic resources like medical equipment or care actors. Anticipating the medical problems, participate, in many cases, in compensating the logistic gap.

*DS (physician): “ The anticipation is to listen to all care actors, analyzing the patient case and to create a collective responsibility to avoid maximum urgent cases. It is better to spend time anticipating and to forecast, rather than spending time on managing emergencies. Exchanging feelings of health professionals around the patient, it is a key to anticipation.”*

Care actors handle current medical issues and anticipate possible future problems; to do so, they depend on their experience and acquaintance with the patient to perceive

signs of worsening of the health status of the patient. Care actors share their impressions on the notebook. For example, the nurse remarks that the patient has signs of lack of oxygen, and before administrating the oxygen he writes a note alerting the physician (Figure 13).

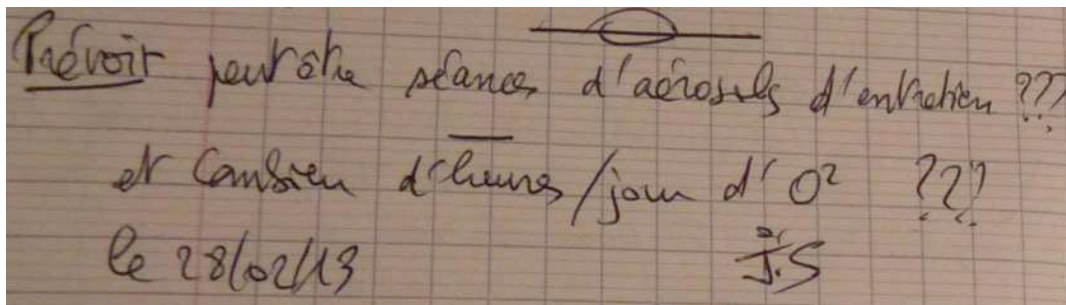


Figure 13: Anticipating the oxygen problem

However, if the care actors see signs of potential risk for the patient, they call each other and try to fix the problem and avoid the emergency. For example, the nurse signals a problem with the patient 'he is suffocating and has stomach ache'. The nurse calls the physician; they discuss the different solutions and the doctor visits the patient the next day (Figure 14).

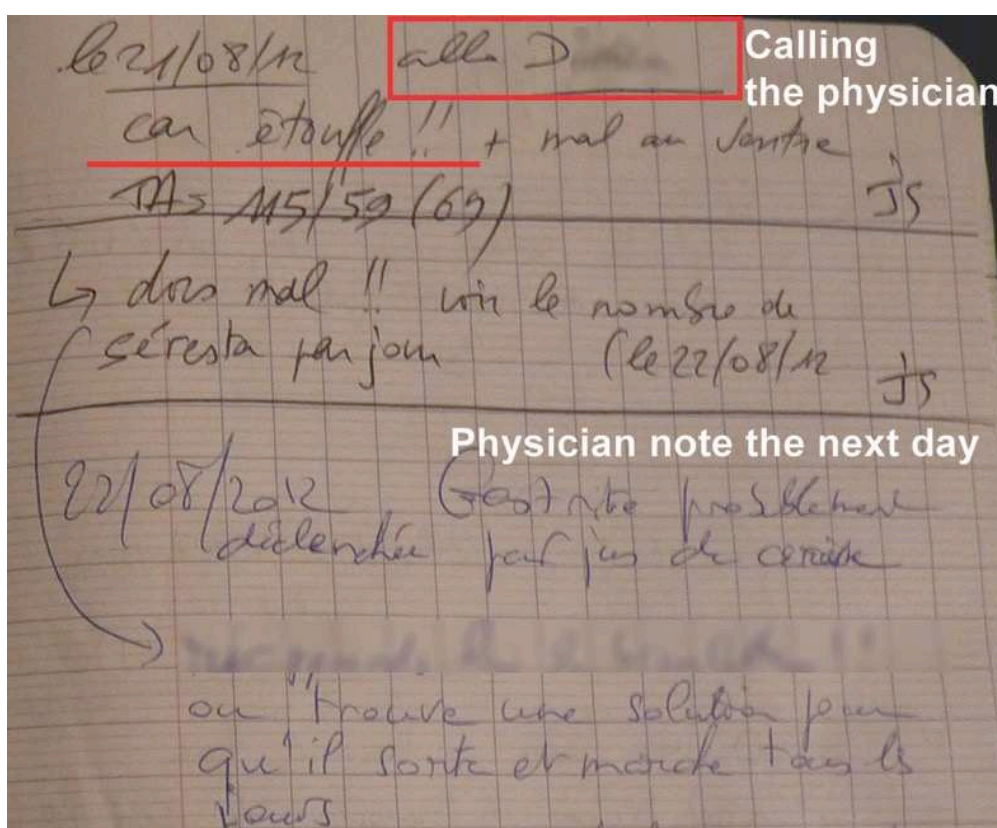


Figure 14: Dealing with emergency

When the problem requires changes in the care plan, all the care actors work together to stabilize the patient's situation. Changes in the care plan might come after an emergency that requires temporary changes, for example if the patient is injured or

broked his/her leg. It could also follow a more permanent evolution in the patient's state of health. The case of Mr. WD illustrates how the care plan changed after diagnosing him with diabetes.

Mr. WD started severe diabetic episodes; the physician asked the nurse to start a surveillance and insulin treatment. The nurse and the patient cooperated to implement the diabetic monitoring. The nurse taught the patient how to take the necessary measurements, and how to document them. The patient recorded the results of his blood glucose tests and the meals he eats. The nurse comes twice a day (morning and evening); he measures the patient's tension and blood glucose. Based on the information noted by the patient, the nurse decides the necessary insulin dose and records all of that in the liaison notebook. The physician communicated with the nurse and followed the progress of the patient condition. Three months later, care actors decided to reduce the nurse visits to once a day.

### 3.3.3.2 Social Issues

Keeping the patient at home safely depends, in many cases, on the implication of informal caregivers<sup>10</sup>. Indeed, when patients are fragile (cognitively or physically, or both), the role of the informal caregiver becomes vital to ensure the safety of the patient. Thus, the care actors watch over the informal caregiver as an integrated part of the necessary efforts to sustain the home care for the patient.

For example, Mr. LD suffers from Alzheimer's disease and heart problems. The patient lives with his wife (his main informal caregiver), who just injured her wrist while gardening. The home-helper called the physician who suggested sending Mrs. LD to the clinic before making the radio image. Once Mrs. LD arrived, the physician managed to see her between two patients. He diagnosed a fracture and contacted the x-ray clinic to make sure she will have the x-ray as fast as possible.

After the x-ray was done, and according to the request of the physician, the radiologist contacted the hand surgeon so the wife had her hand plastered and could come back home later in the afternoon.

The intervention of the physician and the involvement of all the care actors allowed a fast management of the situation (Mrs. LD broken wrist). If not, she might have waited for hours at the emergency room for her radio image. Shortening this process was vital for her role as the main caregiver of the patient.

*DC (physician) "Mr. LD is unable to stand alone, to wash, or to feed himself. Most importantly, he would panic without his wife. If his wife goes to the grocery shop and does not come back in two hours, he will panic."*

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<sup>10</sup> Informal caregivers are persons who do care actives for the patient without being paid for it, usually a spouse or children, but it also might include friends or neighbors



The accident of the wife raises the question of her state of fatigue; this is the first time she falls. She is aging and getting tired. Moreover, recently the wife stopped documenting on the liaison notebook of the patient.

*JSS (nurse): "I think it is necessary that one day, we listen to the couple because I see that we are the end of May, and nothing has been documented for a month. There is something happening with this woman; normally, she is rigorous when it comes to documenting. [...] We risk a degradation of the care in this couple"*

Hence, the intervention of the care actors is not limited to medical care; they are reactive to the modification happening in patients' social environment, and they reorganize the patients' care to ease the charge of the informal caregiver.

The case of Mr. AK illustrates how the care actors take into account the burden of the informal caregivers. Mr. AK is epileptic and paralyzed; he depends for the most part on the care of his wife. Normally, the couple goes on vacation in the summer for two weeks to visit family. However, this year they had a complication, the airline company refused to have the patient on board. The wife decided to cancel the trip. To help the wife maintaining the trip, the nurse proposed to change the organization around the patient so the wife can take some time off.

*JSS (nurse): "She loves her husband [referring AK couple], and she looks after him all year, but she needed a break. We discussed the situation with her, and we put a team in place, the physician, me, and a home helper who comes three times per day to feed him, and his son who accepted to sleep at home during the absence of Mrs. AK"*

### 3.3.3.3 Logistic Issues

Caring for patients at home include tasks like hiring care actors, handling the medical equipment (functioning, maintenance) and modifying environmental safety hazards (like tripping obstacles, stairs without handrails). Logistic issues also include dealing with administrative formalities (ex. asking for prescriptions or medical appointments), as well as addressing daily issues related to medical equipment problems.

Care actors discuss logistic aspects when starting or modifying a care plan; they ask questions like "do we need special medical equipment?" "Can we have the required medical equipment at home?" "Do we need additional care actors?" "Can the patient afford paying for extra care actors?" "Can the patient have financial help for home care services?"

The logistic issues develop to accommodate the changes of social and medical conditions of the patient, as it is the case for Mrs. LD, the main caregiver of her husband suffering from Alzheimer disease. After her wrist injury, she had her hand plastered; this hindered her ability to look after her husband. The care actors proposed increasing the number of hours spent by the home helper, to help the wife and avoid admitting the patient to a care house. Hence, the care actors took into account the patient's situation.

JSS (nurse): "This is a case that will have consequences for the management of her husband because the lady will be more or less disabled, so, we have set up the needed help [...]. As for the husband, he is very attached, as a patient with Alzheimer's, to his routine. You change the routine of this gentleman; he will be like an atomic bomb."

This decision has a cost, and again the care actors discussed if the couple could afford it. The couple did not get any financial support, and they paid the home helper with their money.

DS (physician): "We have realized that the couple paid the home helper, and they did not get any financial help. They did not benefit from the APA [the Elderly Financial Help granted by the general council]. We just told her [the wife] to contact the social worker of the General Council. We know it is going to be a month or two before aid is launched. Even for emergency situations, the General Council procedures are always very long. So we asked her to call at the same time her insurance company because they may pay for the extra hours done by the home helper, as the need for these hours was caused by an injury."

Similarly, the care actors handle logistic issues when maintaining the care plan. Usually, care actors use the liaison notebook to document logistic issues like administrative needs (Figure 15), equipment problems (Figure 16), and organizational issues (Figure 17).

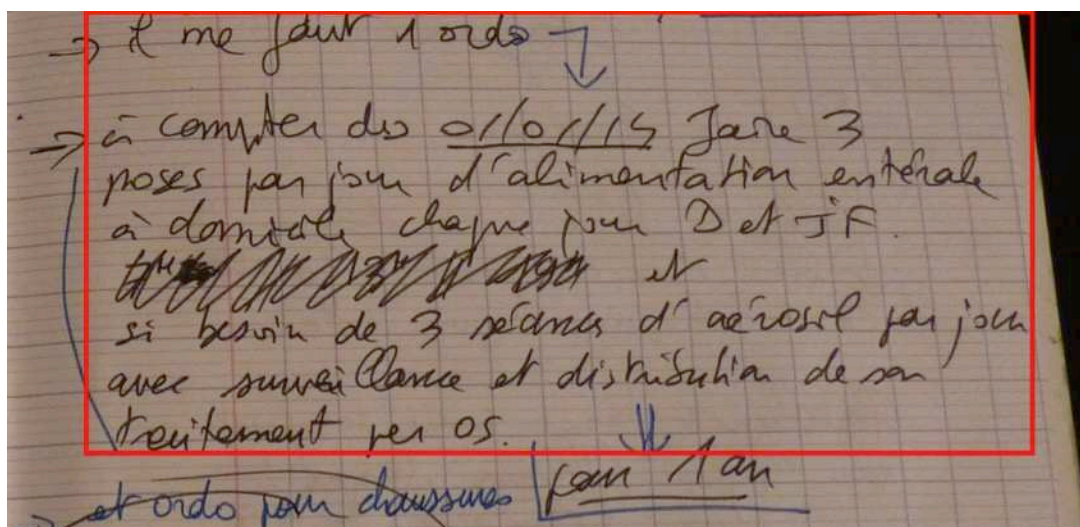
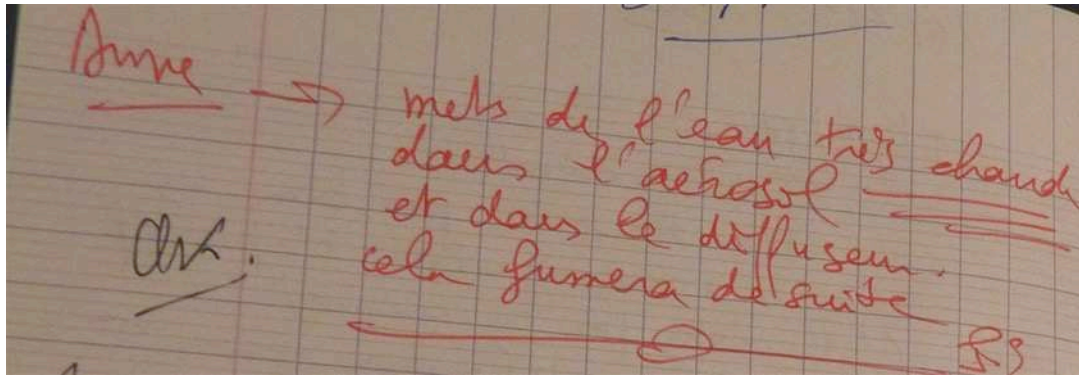
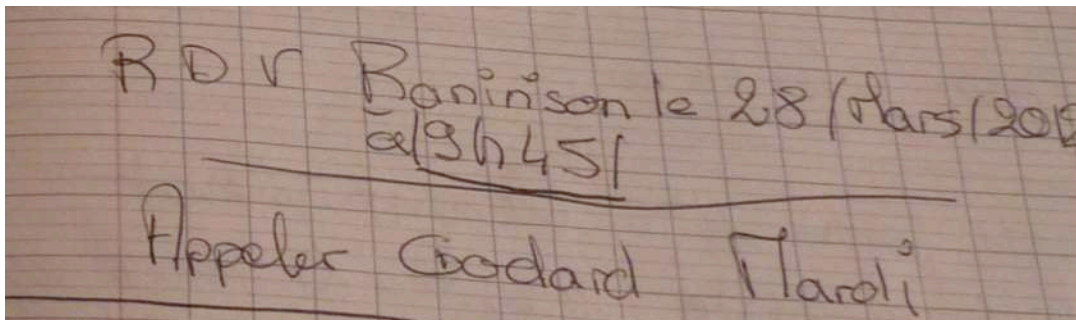


Figure 15: The nurse asking the physician to renew the prescription



**Figure 16:**The main nurse informs the secondary nurse that she should put hot water for the oxygen pump before using it.



**Figure 17:** Documenting a medical appointment and asking to call a medical taxi before

Finally, care actors address logistic issues when modifying the safety environment hazard. The patient's home undertakes changes to ensure the security of the patient at home, as for example when replacing the gas stove by an electric one.

*JSS (nurse): "We are almost expecting the future [...] for example a couple of psychiatric patients, the physician and I are thinking about finding them another, more suitable apartment. You see [addressing the researcher], it goes that far; we will try to find another place for patients."*

All care actors might signal a logistic issue, and all care actors can comment on the issue and propose a solution. For example, the home helper has a problem with the patient's bathroom, she writes a note to inform the physician (Figure 14). In fact, it is difficult for patient to use the bathroom safely due to his state of health; thus, the home helper proposes to install a grab bar. The physician comments that he is aware of the situation and they are trying to change the bathtub with an Italian shower, more adequate for the patient situation. Next, the nurse proposes buying a large basin to wash the patient instead of using the bathtub as a temporary solution (Figure 15).

The home-helper asking if it possible to install a grab bar in the patient's bathroom

The physician answers that he would be ok for the bar but he mentions that they had started the procedure of changing the bathtub with an Italian shower

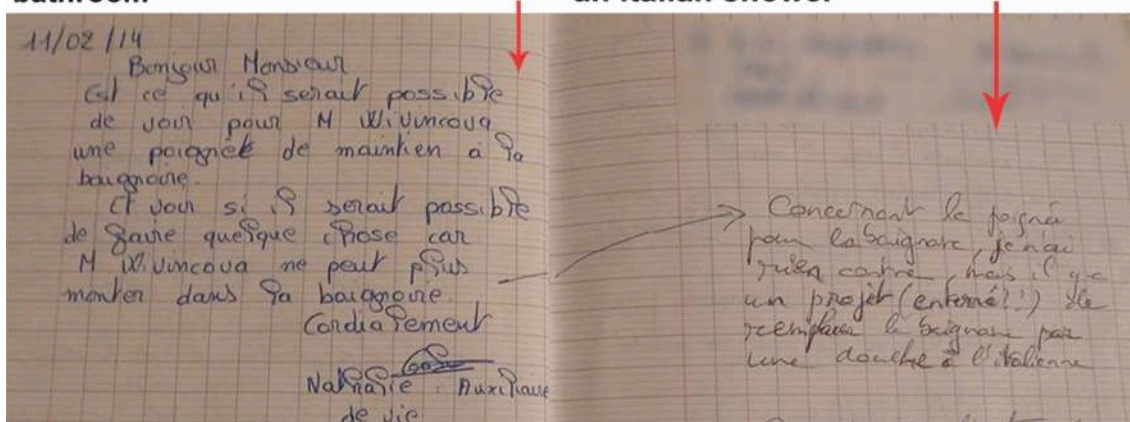


Figure 18: messages handling the patient's bathroom problem

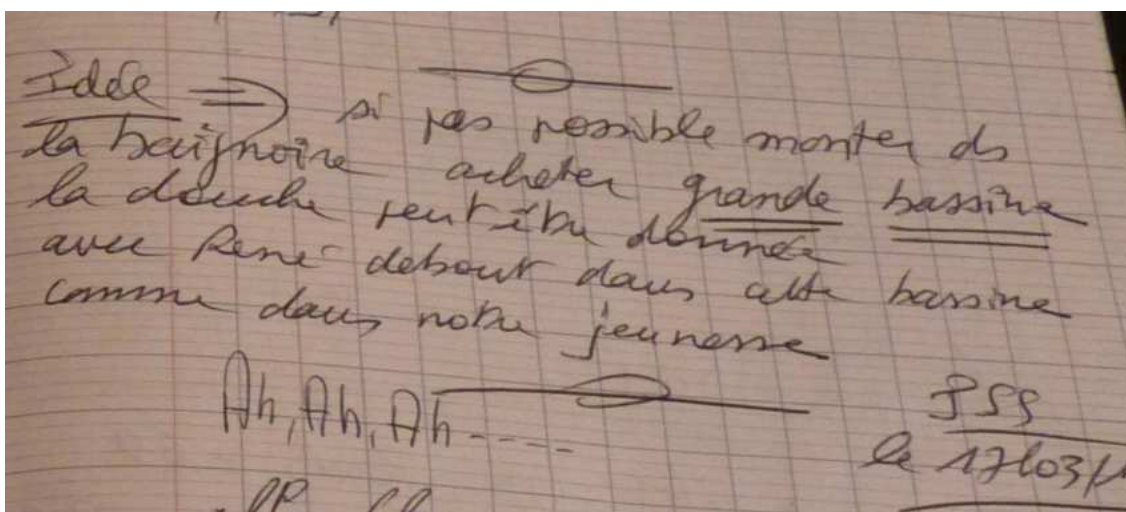


Figure 19: The nurse proposing buying a large basin to replace the bathtub

### 3.3.4 Articulating Different Collaboration Rhythms

We have illustrated above that the care actors face issues spanning medical, social and logistic dimensions. Thus, the care actors have to collaborate to be able to address different aspects of emerging issues and to accommodate the requirements of the evolving situation of the patient.

We have identified two interchanging phases for care actors work rhythm: a “standard” coordination rhythm and the “intense” one:

In the “standard” phase, the patient’s situation is relatively stable, the care actors handle emerging problems individually according to their roles, and they coordinate their work conforming to care plan. In this phase, the care actors might collaborate tightly to handle urgent problems and loosely for less urgent ones. If the problem is urgent, care actors call each others and might meet in the patient’s home.

JSS (nurse) "The phone, DC [the physician] and I, we use it a lot. When there are complications, I use the phone, and DC always answers me, so oral communication is working."

When the problem does not affect the patient's safety, the care actors use the patient's notebook to exchange questions, answers or suggestions. For instance, the nurse remarks that the patient has a high blood pressure, gives the patient the necessary medication, and leaves a note in the notebook for the home helper. In his note, the nurse asks the home helper who cooks the meals to cut down on salt in the patient's diet (Figure 20).

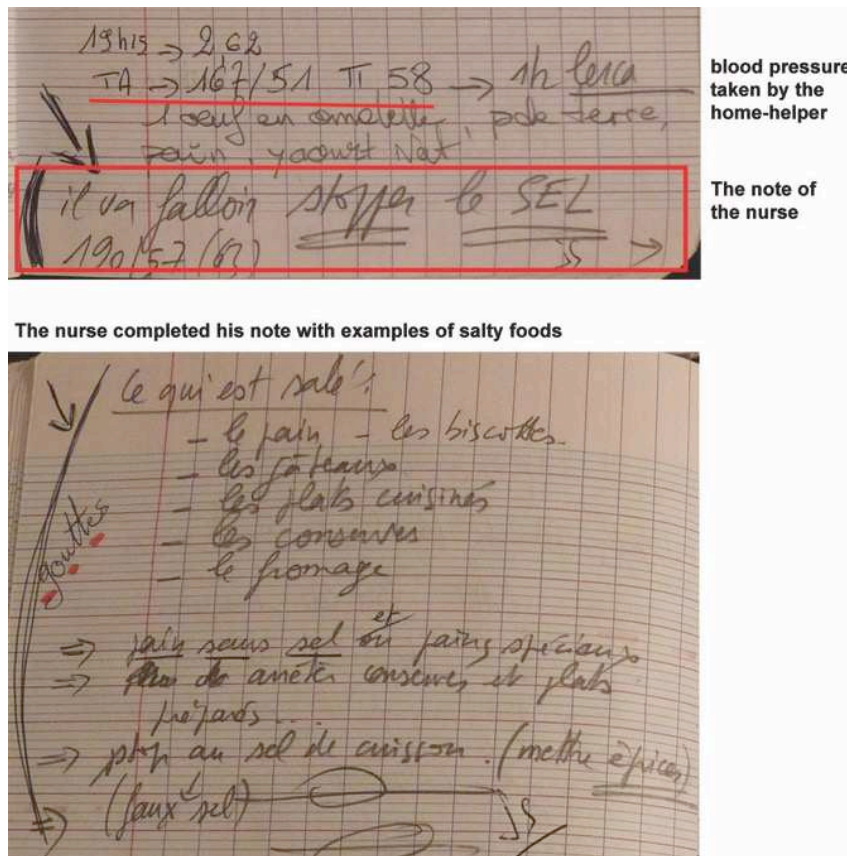


Figure 20: Handling high blood pressure situation

The "intensive" phase starts when unexpected (medical or not) events arise and lead to a crisis that is challenging the current care plan. All the care actors then collaborate in modifying the care plan in order to come back to "normal". Usually, the care actors organize a "care meeting" at the patient's home to characterize the problem.

DC (physician): "This meeting can be initiated when a care actor signals a problem (e.g., a deterioration in the patient's condition), or when the patient is saying something is wrong with the care plan. This meeting allows us to see what is going wrong".

This meeting consists of a discussion of the problem and of the different possible solutions. All the care actors, including the patient, might participate in the discussion depending on the treated issues.

*DC (physician): “The number of participants varies according to the reasons why the meeting was organized. For example, we might discuss a change in the overall care plan or make decisions such as placing the patient in a nursing home, all of that in front of the patient”.*

The care meeting ends with changes in the management of the patients’ conditions. They may decide to include a new care actor, to ask for one-time interventions or to change how the current care actors provide care.

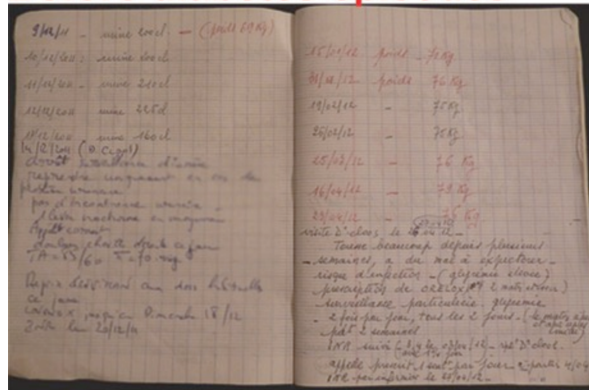
The case of Mr. MD illustrates how care actors work together to adapt the care plan and keep the patient safe at home (Table 3). Mr. MD, 80 years old, suffers from an inflammatory rheumatic disease that evolves in spurts, and the pain justifies a cortisone-based treatment. The patient is treated at home where he lives with his wife (his main informal caregiver). A home-helper comes twice a week to help his wife in caring activities. A registered nurse and the general practitioner visit the patient when needed (for instance when an injection of cortisone is needed). All the care actors (wife, home-helper, nurse, and physician) write their observations in the liaison notebook.

Mr. MD started severe diabetes episodes caused by the cortisone treatment; this triggered a care meeting where care actors, including the wife, reorganized the patient’s care plan. The physician asked the nurse to start a diabetic surveillance and insulin treatment. The nurse and the wife cooperated to implement the diabetic monitoring. The nurse taught the wife how to make the necessary measurements, and how to document them. All the care actors adapted their practices, including the documentation practice as the patient need to keep a record of blood glucose (Figure 21: Changing the style of documentation (freestyle documentation on the left side, and structured documentation on the right side)).

	M	T	W	T	F	S	S	M	T	W	T	F	S	S	M	T	W	T	F	S	S	M	T
Patient	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Red	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Blue
Wife	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Red	Red	Red	Red	Red	Red	Red	Red	Blue	Blue	Blue	Blue	Blue	Blue
Home helper		Blue			Blue				Blue	Red		Blue				Blue			Blue				Blue
Nurse			Blue							Red	Red	Red	Red	Red	Red	Red	Red		Blue				Blue
Physician										Red						Red							

**Table 4: The schedule of care actors visits of Mr. MD, the red color represent care actors tight collaboration in the “intense” collaboration phase, while the blue color represent collaboration in the “standard” phase according to the care plan.**

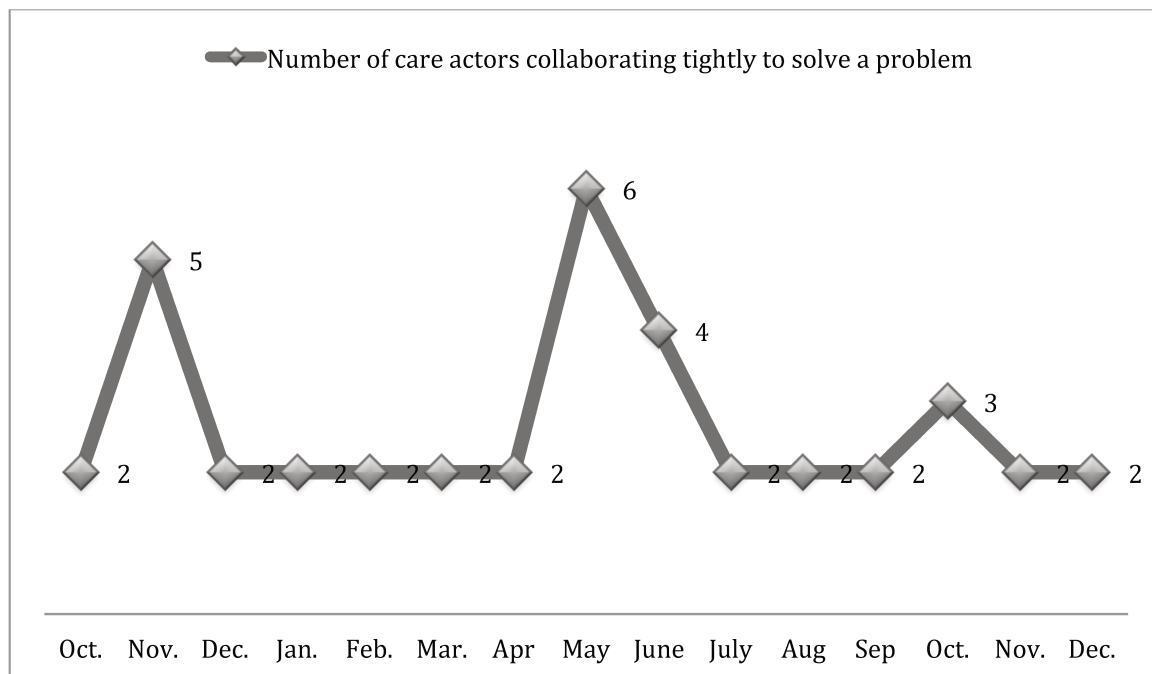
## Before diabetes episodes



## After diabetes episodes

**Figure 21: Changing the style of documentation (freestyle documentation on the left side, and structured documentation on the right side)**

The case of Mr. MD shows how the care actors experience different rhythms of collaboration (Figure 18). To illustrate the impact of emerging issues on the collaboration rhythms, we traced the number of care actors involved in tight collaborative episodes during the period between October 2013 and December 2014. Thus, we can see that some emerging issues triggered the “intensive” phase of collaboration. For example, six months from the diabetic episode, Mr. MD was admitted to a hospital after he has been diagnosed with a prostate cancer. Once Mr. MD has returned home, all regular care actors along with the specialist worked together to enable caring for the patient safely at home.



**Figure 22: Number of care actors collaborating tightly to manage Mr. DR condition from Oct. 2013- Dec. 2014.**

The rhythmic way of collaborating between the care actors allow them to collaborate when it is necessary. Self-employed care actors put a special value on time because of

their overloaded schedules. Having a classic collaboration team, with regular meetings, predefined agenda, and future objectives is not possible with the tight schedules of these care actors, and would not be effective in the fast-evolving context of home care. This way of organizing work allows care actors to cope with evolving team members (due to the nature of self-employed status) and to extend the team competence when needed. In fact, integrating new actors, even for a short period, is always possible and expected.



### 3.4 DISCUSSION AND DESIGN IMPLICATIONS

As we have illustrated above, providing care at home is a complex issue; care actors must adjust their practices and negotiate with patients and their families to successfully perform their work (Bratteteig and Wagner 2013). Home care requires, in addition to stabilizing the state of health of the patient, considering logistic and social issues impacting the quality of life of the patients and their relatives. Succeeding the home care management requires the intervention of different care actors to satisfy medical, social and logistic necessities.

Prior studies in CSCW have explored the complexity of implementing home care networks and care teams. However, whereas previous work has focused on the collaboration among members of inter-professional care teams working within the same organization (Pinelle and Gutwin 2003) or across organizations (Petraou 2007; Amir et al. 2015), our work focuses on the cooperation between self-employed health professionals. These members do not share common protocols or routines to coordinate their work, and they cannot rely on any sustainable information system. In contrast with the shared binder studied by (Petraou 2007), the liaison notebook that we have presented above does not have any predetermined structure because each patient offers a different case and is managed by different care actors. In the context we have observed, collaboration occurs on a voluntary basis, and care actors do not share any infrastructure, contrary to the context covered in the work of (Bossen et al. 2013).

Home care actors work in a solo base, but when their patients' situation grow in complexity, they have the choice either to send the patient to a clinical setting or to collaborate with each other to keep the patient safe at home. Collaboration occurs to accommodate emerging issues or an evolution of the state of the patient. The care actors we met admit the necessity to change their current solo-based practices and work together to create an adequate care plan. We called this situation an **“intense” collaboration phase**. When the situation of the patient becomes stable again, the collaboration between the care actors become looser, and they turn to what we have called a **“standard” collaboration phase**, where they coordinate their activities according to the care plan.

In the **“standard” collaboration phase**, a care actor can communicate with other care actors to find a solution for a challenging issue that goes beyond his/her competencies. If the problem persists, the care actors enter an **“intense” collaboration phase** that starts with the care actors organizing a meeting at the patient's home in which all the concerned care actors (try to) participate. New care actors might also be invited to extend the competences of the care group. Thus, the collective management of care at home evolves according to the patients' situation; new care actors might participate in care, current care actors might change, and the care plan is subject to modification all the time.

We argue that the collective management of home care that we have observed, shows similarities with what Engeström defines as “knotworking” (Yrjö Engeström, Engeström, et Vähäaho 1999):

*“a longitudinal process in which knots are formed, dissolved, and re-formed as the object is co-configured time and time again, typically with no clear deadline or fixed end point”(Engeström 2000, 973).*

Knotworking represents, we believe, a way of collectively re-organizing the work that emerges in a cooperative ensemble which works relatively loosely with an evolving object. Thus, in this pattern, the cooperation happens between semi-autonomous entities (organizations or persons) which normally do not cooperate, yet, in certain cases their cooperation might be the only way to overcome certain challenges.

Furthermore, this pattern of cooperative work emerges in fieldwork with high uncertainty and thus requires dynamic cooperation mechanisms to accommodate contingencies and new requirements. What distinguishes knotworking from the “natural” development of work and collaborative practices is the high reactivity of re-configuring work. This is due to rhythmic nature of collaboration that allows to put together workers who are usually not connected to cope with emerging new requirements. Moreover, the knots do not have a preexisting structure which makes possible the inclusion of unusual combination of cooperative workers, and in some cases the extension of the cooperative ensemble to accommodate new requirements.

In these lights, we can consider that in the case of “e-maison médicale”, the issue that is challenging an existing care plan represents the ‘pulse’ that triggers the formation of the knot that includes concerned care actors and potential other care actors. The issue emerges as a result of the collaboration between some care actors who highlight a problem, and others who propose some solutions. According to the level of emergency, this kind of discussion can take place asynchronously, mediated by the liaison notebook, or synchronously face-to-face or via phones or. When the care actors conceive the issue as challenging for the current care plan, they organize what they call a “care meeting” in the home of the patient, in which they invite the current care actors and eventually new care actor(s). This meeting represents the maturity of a knot. The objective of this meeting is to understand the problem, discuss options and find compromises to re-configure the care plan. Once the knot reaches its objective, the members go back to the standard collaboration phase where they coordinate according to the new care plan, which might include collaboration with new care actors or changes in the current way of organizing the care. Knots might also develop simultaneously to address different issues that arise in parallel. This cycle will repeat itself according to the evolution of the care conditions of the patient.

Finally, the liaison notebook, though underspecified, offers a place for the care actors to discuss their care activities and thus, allow to highlight problematic issues, which will trigger the formation of a knot. The notebook can then be used both as a resource of

information about the issues that a patient encountered, and as a place to discuss how to adapt the care plan.

This reactive organization reassures the patients because they have the feeling that they can count on the collaboration of the care actors when a problem occurs.

However, we identified challenges regarding the sustainability of this kind of knotworking:

(1) **Integrating new care actors.** New professionals constantly join the care ensemble. Current care actors have to train them so that they can integrate knotworking. But due to their very busy schedule, they advise the new care actors to look at the liaison notebook in order to understand their collaborative practices. Unfortunately, the new care actors do not always have the necessary time to fully review the notebook, because the time they spend with a patient and the frequency of their intervention vary depending on their profession (from 10 minutes to 2 hours per visit and from 3 visits per year to twice per day). In fact, reading the notebook of a patient (particularly for the first time) takes a considerable amount of time, especially to be able to identify the most significant information or to obtain a global vision of the patient's situation and how the collaboration occurs.

(2) **Nurturing the ongoing role negotiation.** The roles of the care actors change according to the evolving situation of the patient. For instance, a physician who is usually at the center of the care organization might have secondary roles according to the addressed issue: solving problems related to the design of a bathroom to avoid falls, or to the difficulty of a patient to walk will not involve the same care actors. In the collective approach of home care, the center is changing according to the nature of the emerging problems to be solved. While all the care actors can participate in addressing the emerging issues, the leading care actors change according to the addressed issue. This makes it then difficult for the care actors to find their place in this dynamic collective management. Thus, many care actors focus on their individual tasks and watch the dynamic role negotiation "from outside". This collaborative management of care represents a real shift from the traditional hierarchical organization that is dominant in the health domain (especially in France) to a more horizontal and dynamic organization in which all the care actors have a role in defining and modifying the care plan.

(3) **Ensuring the constant participation of all the care actors.** The rhythmic collaboration affects the involvement and the motivation of the care actors. While the care actors participate actively into the intense collaborative episodes, it is difficult for them to keep the same quality of coordination during the "standard" collaborative phases. Having very busy schedules, the care actors would not dedicate time for coordination activities if they would not see a direct benefit. The situation becomes problematic when a patient is encountering a relatively long "standard" collaborative phase.

Acknowledging these challenges, and based on our analysis of the collaborative practices of the care actors, we make the hypothesis that Information and

Communication Technologies (ICT) can offer the care actors a way to visualize their collaboration, which, we assume, will enhance their motivation and facilitate the integration of new care actors. We believe that the collaborative practices among evolving members organized in knots can be supported by offering a tool that traces the evolving objective (patient's quality of life) and that allows the care actors to negotiate their roles and practices. In the next chapter, we present the socio-technical system that we have proposed, developed and tested with the care actors which we have followed during the our fieldwork.



## **4 DESIGN AND EVALUATION OF THE CARE APPLICATION**

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Acknowledging the challenges we identified in the previous chapter, and based on our analysis of the collaborative practices of the care actors, we make the hypothesis that Information and Communication Technologies (ICT) can offer care actors a way to visualize their collaboration that will enhance their motivation and facilitate the integration of new care actors. We believe that a tool supporting collaboration between evolving members organized in knots has to consider tracing the moving objective (in the case of e-maison médicale this will be the patient's quality of life) and allow them to negotiate their roles and practices.

In this chapter, we present the design process of the CARE (Classeur pour une Approche en Réseau Efficace – Binder for an efficient networking approach) application. First, we introduce the main design principles that we followed to build CARE. Then, we explain how we translated these design principles into features that we illustrated with mock-ups. Next, we report on the feedback of the care actors on the proposed mock-ups, and we present the application through a use scenario. Finally, we report on the pilot study that we conducted for 20 weeks in the homes of the patients.

#### **4.1 DESIGN PRINCIPLES**

In this section, we present the main design principles that we propose for a system aiming at supporting knotworking among care actors.

Supporting the collaboration among care actors who form knots at certain moments is challenging because the members of the knots members are constantly evolving. As we illustrated in the previous chapter, the situation of the patient changes and thus, the care actors who participate in the care activities change too. Thus, collaboration occurs between unpredictable combinations of care actors.

As we showed in chapter 3, preserving the quality of life of the patients at home is a complex issue that relies on addressing medical, social and logistic issues. Thus, we think that a system supporting these collaborative practices should be open enough to allow care actors coming from different professions to participate in documenting the information concerning the patient.

We have also learned during our field study that the care actors need to discuss with each other about the condition of the patient, but due to their overloaded schedules, they rarely meet. Thus, we have to support their continuous discussions without disturbing their current workload. Exchanging messages about the patient could enable care actors to address complex issues by discussing problems in an asynchronous way.

Finally, as the home of the patient is the place where the care takes place, we believe that the application should be made available at the home of the patient, under the control of the patients or their family members. This would allow the care actors to get information when visiting the patient and at the same time to enable the patient and the family to play a role in facilitating or controlling who will use the application.

Following the above-mentioned considerations, and bearing in mind the knotworking process in which the different care actors are engaged in, we identified three main principles to support collaborative practices of care actors for care at home:

#### **4.1.1 *Tracing the challenging issues in patients' trajectory***

Making the trajectory of the patient visible facilitates the integration of new care actors by giving them the necessary information about the patient. In fact, the care plan reflects the current condition of the patient, but does not offer the whole story. Tracing the challenging issues that arise could provide a vision of the case of the patient, and thus, allow the care actors to understand the rationale behind the current care plan. To support this global vision, we suggest presenting a timeline in which the care actors could mark the turning points in the situation of the patient. These marks can be annotated to explain changes in the care plan.

The patient's trajectory will trace the medical issues but also the social and logistic events related to a patient, that different care actors have to be aware of. For instance, when the patient's condition evolves and requires having a new medical equipment at home (ex. oxygen pump), it is useful to know when the equipment is available at the home of the patient and to have some information about when to use it and how to handle it.

Thus, the timeline of the patient offers to the current care actors a visual result of their collaboration. At the same time, it offers new care actors necessary information to participate in the care process.

#### **4.1.2 *Enabling a discussion-based documentation***

Keeping trace of messages exchanged between care actors and grouping messages that address the same issues in a discussion thread provides a flexible way of documenting information about the patient.

Firstly, it enables care actors coming from different professions to explain their concern or request. In fact, it allows care actors to not only document the facts about the patient's state of health but to also explain or comment the documented information and what do they think this information might implicate. For instance, if a nurse is only documenting physiological values, these values may have no meaning for the home helper. It is then important to provide a system that is flexible enough so that the nurse can comment on the data, and "translate" it to other professions (e.g. "the patient has to cut down the salt in his diet").

Secondly, it enables providing a context to the documented information. For instance, the high blood pressure of a patient is a medical observation that can be explained or correlated with the type of food s/he was eating or the social situation that s/he was experiencing (for instance fearing her/his upcoming surgery, or attending a birthday party).



Moreover, a discussion-based documentation is aligned with the current way the care actors solve their problems and adjust their practices: the collective management of a patient at home is based on the interaction with other care actors to ensure a certain stability of the situation of the patient, which implies a continuous negotiation of the roles and tasks the care actors should fulfill.

Finally, a discussion-based documentation allows new members to have a look on how collaboration happened between previous members, and thus, it eases the participation of new care members in the discussion. The participation of previous and new actors will offer a more complete vision about the situation of the patient, which is essential for identifying issues that might trigger the formation of knots.

#### **4.1.3 *Offering an indexation of documented information***

The open indexation allows care actors to flag a part of a message (a physiological measure, a comment, a specific demand...) that they identify as important for the collective management of the care plan with a tag. This indexation offers a way to capture the elements emerging from the practice to help current actors highlighting important information that have to be considered when making decisions. Knowing that each patient offers a unique case, care actors cannot predict what are the kind of information they will document or need to achieve their work, and they cannot either predict what kind of issues they are going to address. The wording of the tag will then have to be chosen by the care actor or selected from a list. For bootstrapping this list of tags' values, we find essential to combine the material collected from fieldwork (existing notebooks) with new tags created by the care actors using the system. An important and interesting aspect of this tagging solution is that it preserves the conversational context and the particular situation in which the information is collected.

On top of highlighting the significant changes in condition of the patient, which is key, these tags also permit to enhance readability. In fact, according to their role in the care plan, the different care actors focus on different information. We then suggest to use the tags to provide different points of view according to the interest of the different care actors e.g. (Cahier, Zaher, and Isoard 2010).

## 4.2 DESIGN DECISIONS

Here, we explicit the decisions we made when designing the CARE application, willing at the same time to follow the design principles we listed above and to acknowledge our logistic limitations.

First, privacy issues shaped our design decisions. We faced the dilemma of opening the system for all the different care actors, and the restriction of sharing the medical information with some of care actors, like home helpers and family caregivers. Thus, we decided to keep the tablet under the responsibility of the patients who can decide if they want to give the tablet to a particular care actor. We also made the decision of keeping the patient's information locally and to not transmit anything to a server. We are aware of the limitation of such approach for backup issues, but we chose this as first step validation, before struggling with administrative approval. In fact, sharing medical information on a server, even for a small experimentation like we were planning to do, requires following very strict regulation and might force us to exclude some of the care actors. Besides, the care actors are skeptical about not being able to control who might have access on the server. In fact, many health professionals in the primary sector are not in favor of the government-support project of a shared medical record (Dossier Médical Partagé- DMP), as they fear that private insurance companies might have access to medical records, and use them for bad reasons. This represents, in their opinion, a violation of privacy and medical secrecy.

Second, though we can trace who changes the information in the database of the application the information is not currently visible in the user interface. In this decision we are making the assumption that the professional context permits to trust the users.

Third, to enhance the awareness between care actors we provided a calendar in the patient profile where the visits of the different care actors would be represented by colored rectangles. Users can press on the day in the calendar to see the names of the care actors; this information is generated automatically when the care actor accesses the application (Figure 25).

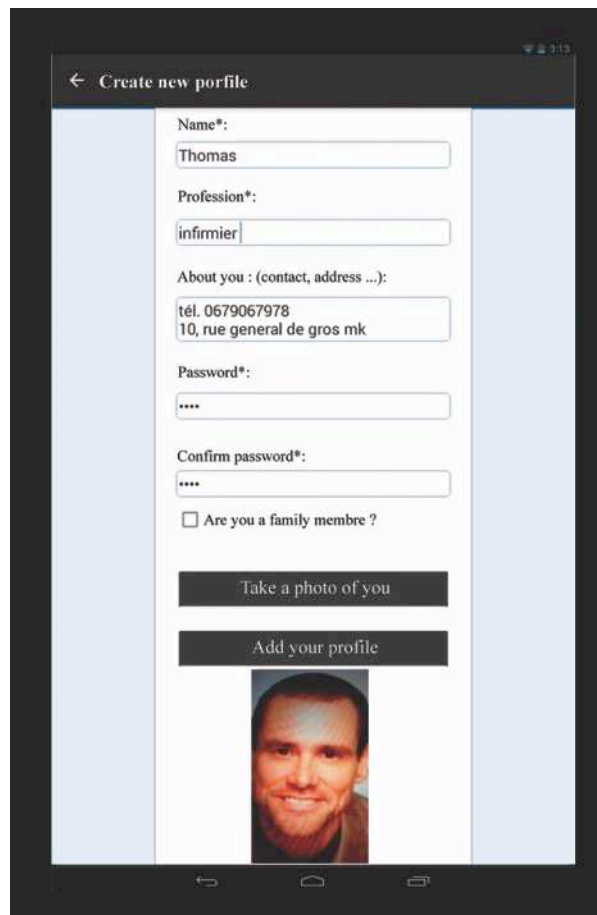
Finally, taking into account the little time the overwhelmed care actors can dedicate to the use of CARE we privileged simplicity of use and rapidity of learning. Thus, we chose a small tablet, because the majority of the care actors are used to use smartphones, and a tablet offers a better readability and a similarity of use.

### 4.3 TRANSLATION INTO MOCKS-UP

In this section, we explain how we implemented the design implications listed above into technical functionalities. The mock-ups that we present here illustrate the resulted solution. We used these mock-ups in our first design workshop with care actors (mentioned in section 3.2.1).

The application aims at supporting knotworking by supporting the documentation of the story behind the evolving objective and by providing new actors with tools to integrate the care team. In our case, the objective of the care actors is to preserve the quality of life of their patients, and thus, the proposed solution supports documenting the care trajectory of the patient, including the medical, social and logistic issues.

The application supports the dynamicity of the care teams through allowing new care actors to access the application and participate in the care of the patient. For the care actors who intervene regularly, they can create a profile with their contact information (Figure 23).

The image shows a mobile application interface for creating a new profile. The title bar at the top is dark grey with a back arrow and the text 'Create new profile'. The form is centered on a light blue background. It contains several input fields: 'Name\*' with the text 'Thomas', 'Profession\*' with 'infirmier', and 'About you : (contact, address ...):' with 'tél. 0679067978' and '10, rue general de gros mk'. There are two password fields, 'Password\*' and 'Confirm password\*', both containing four dots. Below these is a checkbox labeled 'Are you a family membre ?'. At the bottom of the form are two dark grey buttons: 'Take a photo of you' and 'Add your profile'. Below the second button is a small square photo of a man's face. The bottom of the screen shows the standard Android navigation bar with back, home, and recent apps icons.

**Figure 23: Create new care actor profile**

For non-regular care actors, for example a specialist doctor, they just have to enter their name and profession to access the application (Figure 24).

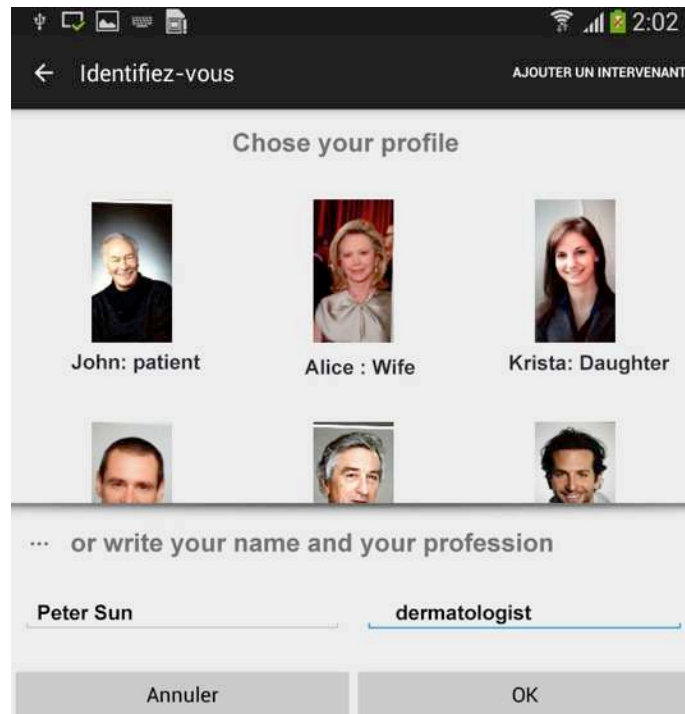


Figure 24: Access the application by entering the name and profession

#### 4.3.1 *Tracing the challenging issues in patients' trajectory*

In our proposition, we provide a dynamic patient profile to support documenting the necessary information to support medical, social and logistic aspects of home care.

The care actors can edit the patient profile to add interesting information for the management of their patient. The application offers a space for a description of the patient, which leaves the care actors the possibility to decide what is important to know about this patient (Figure 25). The description meant to be edited by all regular care actors (who have created their own profiles).

In addition to this description, the patient profile page includes tables that group information tagged in care actors messages (Figure 25). Thus, a care actor can chose to tag a part of the message as an alert (for example "the felled down"). Collecting this information provides an idea of the condition of the patient; for example, the fact that the patient is falling frequently might signal a deterioration in his state.

Thus, through the patient profile, we can trace the important events that affected or might affect the current care plan. These events are ordered chronologically, which offers a vision of the patient trajectory. If necessary the care actors can trace back the main message in which this event was tagged.

**John : Patient** **Edit patient info.**

**Address :** 24 Lorem ipsum dolor sit amet, consectetur adipiscing elit.  
**Telephone :** 03 334 457

**Taille** 1,65 m **IMC :** 23,51  
**Poids** 64,0 kg  
**Groupe sanguin** O Rh +

**Antécédents**

Antécédents médicaux et facteurs de risque  
Hypertension artérielle (1975)  
Hypercholestérolémie (1983)  
Diabète de type 2

Antécédents chirurgicaux et obstétricaux  
Appendicectomie (1946)

Antécédents familiaux  
Père : Hypertension artérielle

Allergies et intolérances  
**ALLERGIE À LA PÉNICILLINE**

**Constantes Physiologiques**

Taken by	information	Date	Hour
Tomas	T° 38- TA 13/9- P 88	22/10/2014	16:32
Tomas	T° 37- TA 16/10- P 72	01/10/2014	16:32
Tomas	T° 36.9 - TA 12/8- P 84	15/09/2014	16:32

**November 2014**

S	M	T	W	Th	F	S
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31	...	...	...

**Write the subject of your message**

Write your message here...

Cancel OK

Figure 25: Patient profile

#### 4.3.2 Enabling a discussion-based documentation

The CARE application offers a place where care actors can exchange messages (Figure 26). Care actors can create a new message by pressing on the button “New message”, comment the other messages by pressing on the button “reply”, or they can acknowledge that they have read a message by pressing on the “ok hand” button. When a care actor replies or comments a message, a link appears at the bottom of the message indicating the name of the person who commented it. Exchanged messages are presented in a reverse chronological order, (i.e. the most recent message is shown first), we make the assumption that care actors read the messages frequently and that they are more interested in recent events.

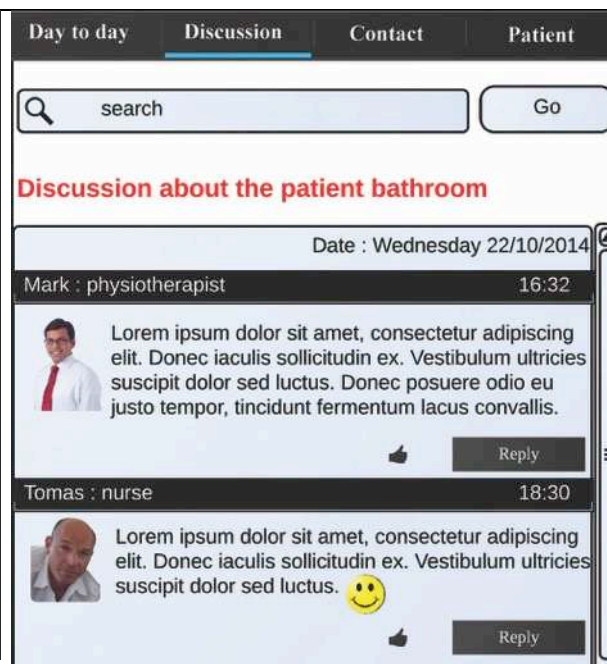


**Figure 26: Day to day follow-up tab**

All the messages that belong to the same thread in the day-to-day follow-up can also be seen grouped together in the discussion tab (Figure 27). Thus, care actors can identify groups of threaded messages (comments and answers) to trace issues that might trigger a change in the care plan. In other words, CARE allows the care actors to easily identify the ongoing debated issues. A discussion is labeled with the title and the author of the first message and the number of messages it contains (Figure 27). The care actor can click on the discussion to browse all the messages it contains in a chronological order (Figure 28).



**Figure 27: Discussions tab**



**Figure 28: One discussion thread that contains 10 messages**

Finally, we offer regular care actors profiles; this enable other care actors (regular or one-time) to identify them in discussions (Figure 29). The application offers also a list of the current care actors accessible via the “Contact” tab, where users can see the contact information.

When clicking on the profile picture of a care actor, we can get more details about the activity of this person, like the list of messages recently posted by him/her and the history of his/her visits (Figure 30).



Figure 29: List of regular care actors



Figure 30: Care actor profile

We also decided to link the messages of the care actors with their names, professions and photos (Figure 31). In fact, tracing the activity of an actor is key in medical context because it lends credibility to the exchanged information and engages the care actor's responsibility.

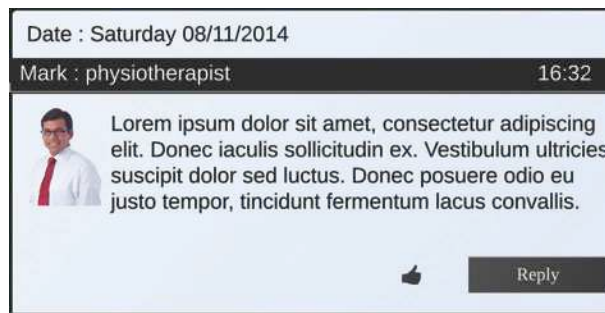


Figure 31: Message of one care actor

#### 4.3.3 Offering an indexation of documented information

The application allows care actors to organize the information into categories in three different ways:

First, care actors can store the information in a specific space, for example the list of medications and the information could be stored in the description box of the patient profile.



Then, when creating a new message, care actors can label the message as important, by checking the box “important message” (Figure 10); they might use this function when they need another care actor to be aware of the situation and to address it. When a message is identified as important, it will be the first to appear in the thread regardless its date of creation, until a care actor addresses the issue and marks the message by pressing the ok hand button.

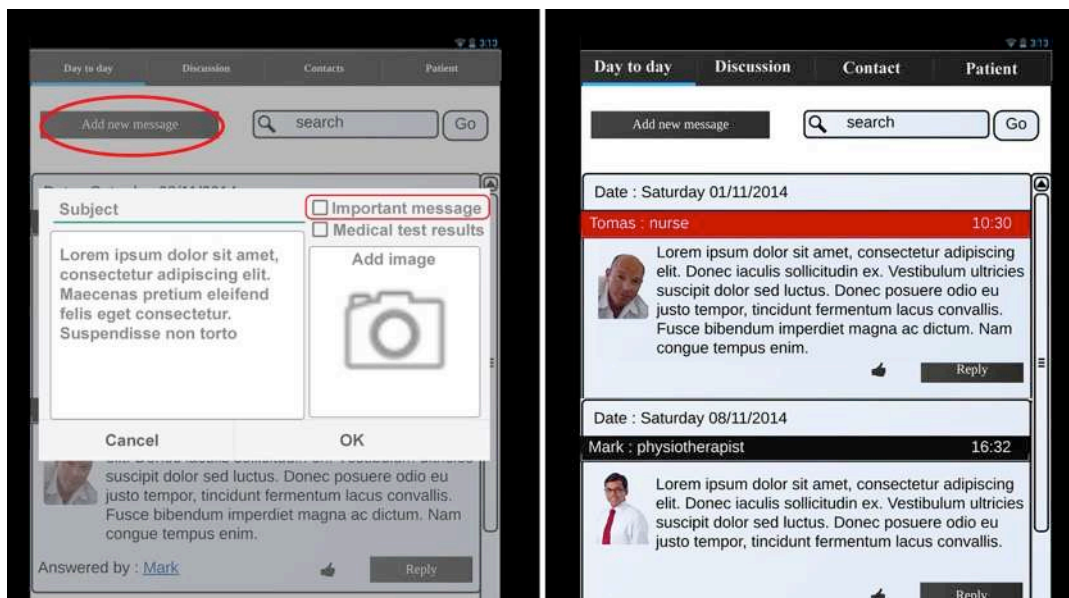
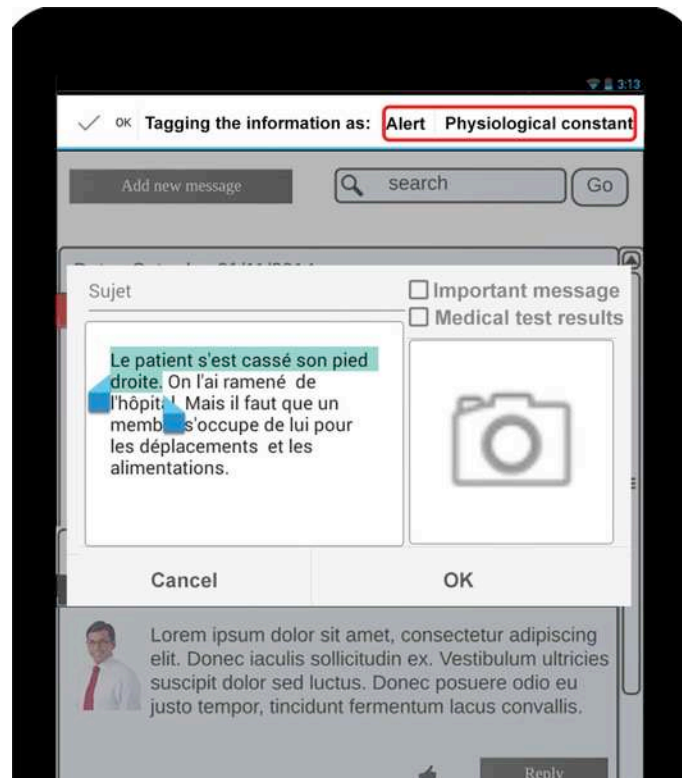


Figure 32: Labeling a message as important

Messages can also be labeled by checking the box “test results” (Figure 10). In so doing, the message will automatically be grouped with all the other messages related to medical test results. The care actors can take a photo of printed test results and comment on it in the message or they can simply indicate the results in a text message. The application does not aim to provide an archive for the medical tests but offers a shared place for the information that is required by the care actors to coordinate their activity, including some results of medical tests.

Finally, the application allows care actors to flag a part of a message either as an “alert” or a “physiological constant”. Our aim is to start with these two tags as a first step before providing a list of tag that could be created by the care actors themselves. In fact, moving from the current practices (with the paper-based liaison notebook) where the care actors do not have any categories for the documented information, to our indexation proposition is not obvious; some care actors were skeptical when we proposed the tagging feature in the interviews and the discussion sessions. Thus, we decided to start with the two tags which emerged from the fieldwork. In the message box, when care actors select a word or a phrase, a toolbar appears on the top of the box, in which they can choose to tag the selected information either as an “alert” or a “physiological constant” (Figure 11). The tagged information is highlighted in the message and added to the patient’s profile as shown in (Figure 25).



**Figure 33: Tagging a part of the message**

In order to assess the adequacy of these first propositions, we organized a design workshop with six participants: three home-helpers, a registered nurse, a physiotherapist and a general practitioner. We used the mock-ups and scenarios to illustrate our interaction design options.

We used three scenarios to address the collaboration of regular actors and the participation of one-time actors in the collective management of patients at home:

- The first scenario described the intervention of a nurse to illustrate how the care actors could access the application, add a new message, read old messages and reply to questions asked by other care actors.
- The second scenario described a consultation at the clinic where the general practitioner is working to illustrate the interest of grouping information for the care actors who do not intervene on a regular basis.
- The third scenario described the situation of a patient who needs to travel to spend a week with his family to illustrate how the application can help completely new care actors to easily get an idea about the patient's situation.

In the next section, we report the feedback that we collected during the workshop.

#### **4.3.4 First feedback**

When we presented the different design options, the care actors acknowledged that the scenarios correspond to the way they are currently documenting the situation of the patient (chronological follow-up), while allowing an automatic synthesis that may be very helpful during emergency situations or when a new care actor is entering the network.

During this workshop, the care actors discussed the opportunity to give access to this application to one-time care actors. They all agreed that a one-time care actor should have access to the synthesized record about the patient, the contact information of the regular care actors, and the day-to-day follow-up. In addition, they should be able to post messages. They also wondered about the best way to inform one-time care actors about how to use the tablet and they suggested sticking a note on the back of the tablet to explain how to access the information and post messages.

The care actors discussed the role of this application in anticipating emergencies. They all believe that a phone call is the best way to handle an alert when it takes place, but they also thought about the potential of the application in alerting a degradation of the situation that is not an emergency but might lead to an emergency.

We had many suggestions related to the usability of the application, mainly related to the way we should present the list of medication. The care actors suggested for example to add a column with the medical dosage. The care actors doubted that a new participant would trust the drug list in the application (without the verification of the doctor). Thus, some care actors argue for the need of such a list and whether it is worth the time to add all the medications (that could represent a list of more than fifteen drugs for some patients). At the end, they agreed that it is essential to keep a complete medication list as it provides the doctor or the pharmacist the required information to prevent potential problems.

The feedback from the workshop confirmed our first design options, and emphasized the importance of opening the management of patients at home for all potential care actors around the patient. However, a discussion arose about privacy and security issues. Indeed, the information that is shared among the care actors is considered as a “shared secret” in a professional context. This situation does not totally conform to the privacy rules of the healthcare system in France, but is tolerated by the patients (and/or their entourage) because it is easing the collective management of their case. This discussion highlighted the gap between regulatory privacy rules protecting patients’ data and the practical needs to integrate all the care actors in the home care management.

## 4.4 THE APPLICATION (CARE<sup>11</sup>)

In this section, we present the main features of the CARE application that we developed following the feedback that we presented above. We illustrate the use of the application by scenarios.

### 4.4.1 *The case of John, a patient suffering from the Alzheimer's disease*

We created this case to illustrate how the application can be used in real situation, the case represent a mix of the cases of several patients that we encountered during the fieldwork.

John suffers from the Alzheimer's disease, as well as heart problems that are both under control. However, he suffers from an inflammatory rheumatic disease that evolves in spurts, and the pain justifies a cortisone-based treatment.

John lives with his wife Alice (his main informal caregiver) and he is watched over by his granddaughter (a general practitioner living in another city). A home helper comes twice a week to help Alice in caring activities. A registered nurse visits the patient when needed, particularly when John needs cortisone. John's general practitioner also visits home when needed.

Recently, John had multiple severe diabetes episodes caused by the cortisone treatment; the general practitioner asked then the nurse to monitor John's blood glucose (blood sugar) to avoid complications.

Alice (the wife) was asked by the nurse to keep track of John's activities. She started to write down what, when, and how much he eats, and to make notes about his physical activity. This record, along with the results of the test of blood glucose levels, will enable the care teams to see the impact of these factors on John's blood glucose and to adapt his diet and treatment.

Previously, the regular care actors used a paper-based liaison notebook to keep a record of John's situation. Now, the care actors are using the CARE application installed on a tablet, which allows them to exchange messages, solve problems and coordinate their work. The care actors have adopted the CARE application to enable the communication with less regular care actors (ex. the cardiologist). All the regular care actors (wife, home-helper, nurse and physician) have accounts on CARE so they can access the application to read and write messages. John has a profile created by his wife and the general practitioner; his profile includes information about his medical history, and his current medication.

For now, John does not have a formal diabetic surveillance with a dedicated notebook; the different care actors use the CARE application to collectively manage his health status.

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<sup>11</sup> CARE stands for Classeur pour une Approche en Réseau Efficace, which means "binder for an efficient network approach" in French.

In the following, we present three situations of use to illustrate how the different functionalities of the CARE application might support the collaboration between the different care actors.

#### 4.4.2 Consultation with the general practitioner

John is not feeling well; his wife Alice called the general practitioner and took an appointment. Once they are at the clinic, Alice explains that John had difficulty sleeping and that he is losing weight. The general practitioner asks her some questions and takes John's tablet.

The general practitioner opens the CARE application and chooses "Suivi quotidien" (daily follow-up) to see if he can get additional information (Figure 34). A list of all the care actors who take care of John is presented, and the general practitioner chooses his profile and enters his password. The general practitioner scans all the messages since the patient's last visit; the first thing he notices is the message of the nurse that is labeled as important (with red banner). The message of the nurse indicates that the patient suffers from a high level of blood sugar (Figure 35).

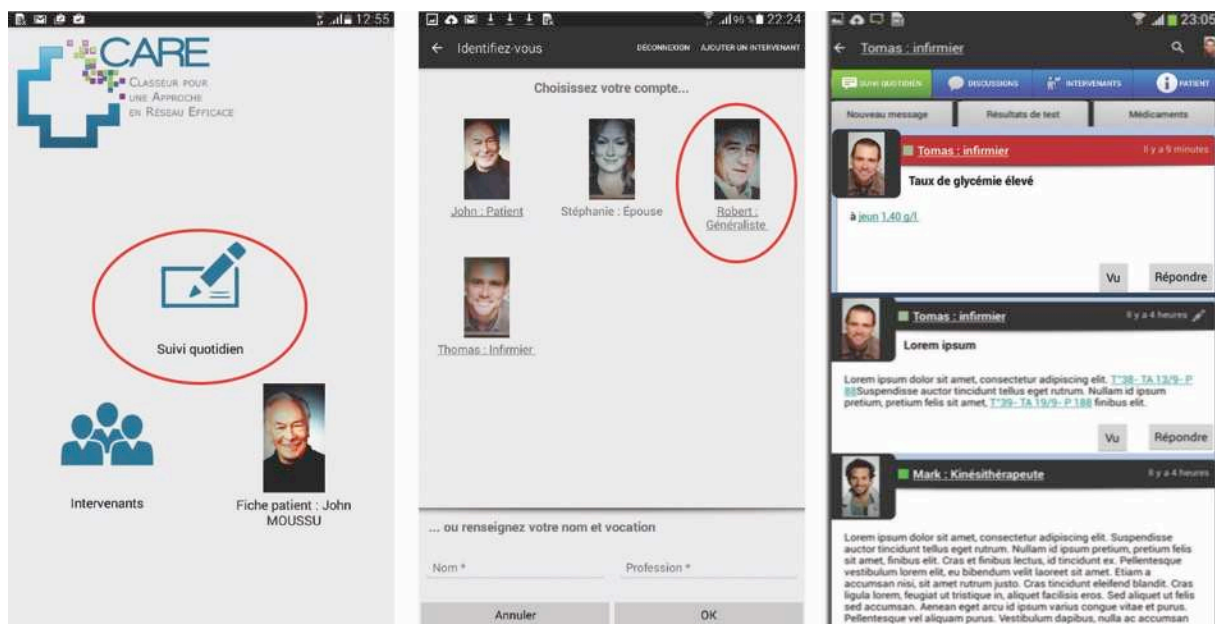
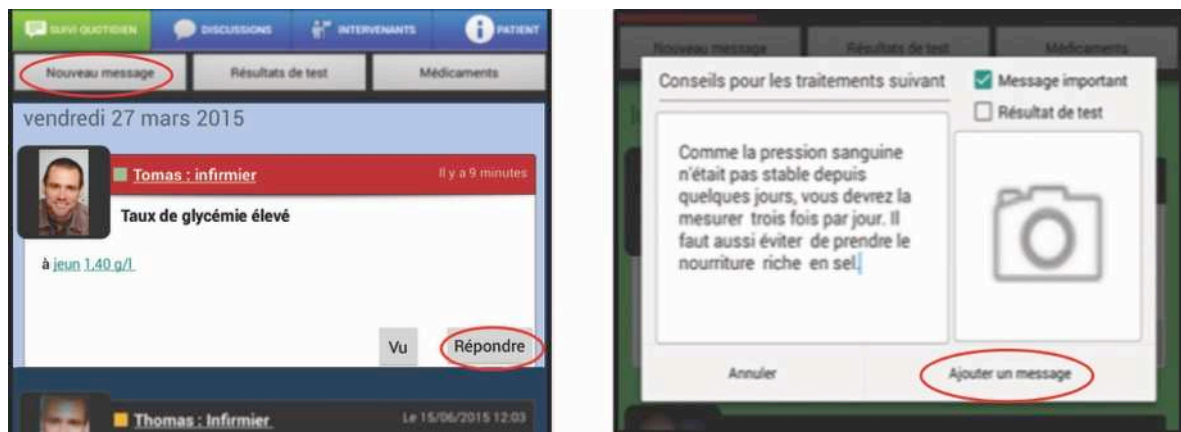


Figure 34- Navigating the CARE application to read messages

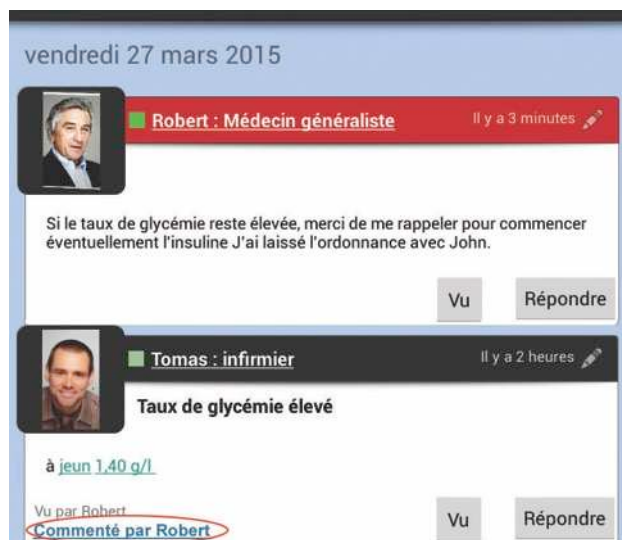


**Figure 35- Reading an important message, and commenting the patient's visit**

After examining John, the general practitioner prescribes a new medication to help him falling asleep, and asks John's wife to weigh John daily and to keep a record, and gives her a new prescription for the nurse. Finally, the general practitioner adds a message in which he answers the nurse and informs the other care actors about the visit (Figure 35).

#### **4.4.3 An intervention of the nurse at home**

The day after John visited his general practitioner, the nurse checks John's blood sugar and finds that it is still high. The nurse opens CARE to check if the general practitioner left a comment on his message, and presses the link to see the comment (Figure 36).



**Figure 36: Following a comment of Robert (the general practitioner)**

In his comment, the general practitioner informs the nurse that he made the necessary prescription in advance and gave it to the patient, but he asks the nurse to call before using the prescription.

The nurse calls the general practitioner so that they can decide together to start the new medication. Finally, the nurse writes a message to report this decision and adds the new drug to the list of drugs (Figure 37).

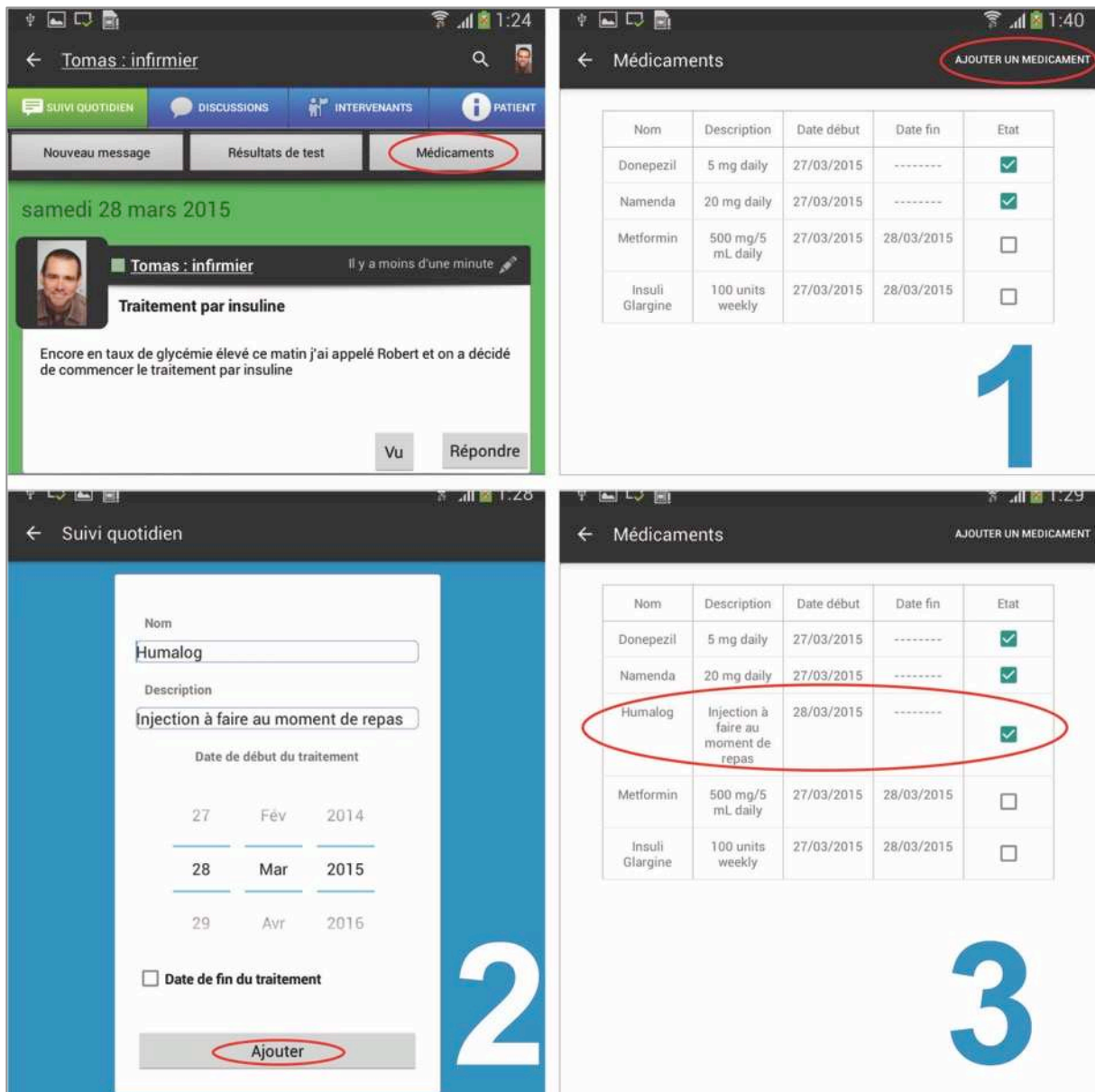


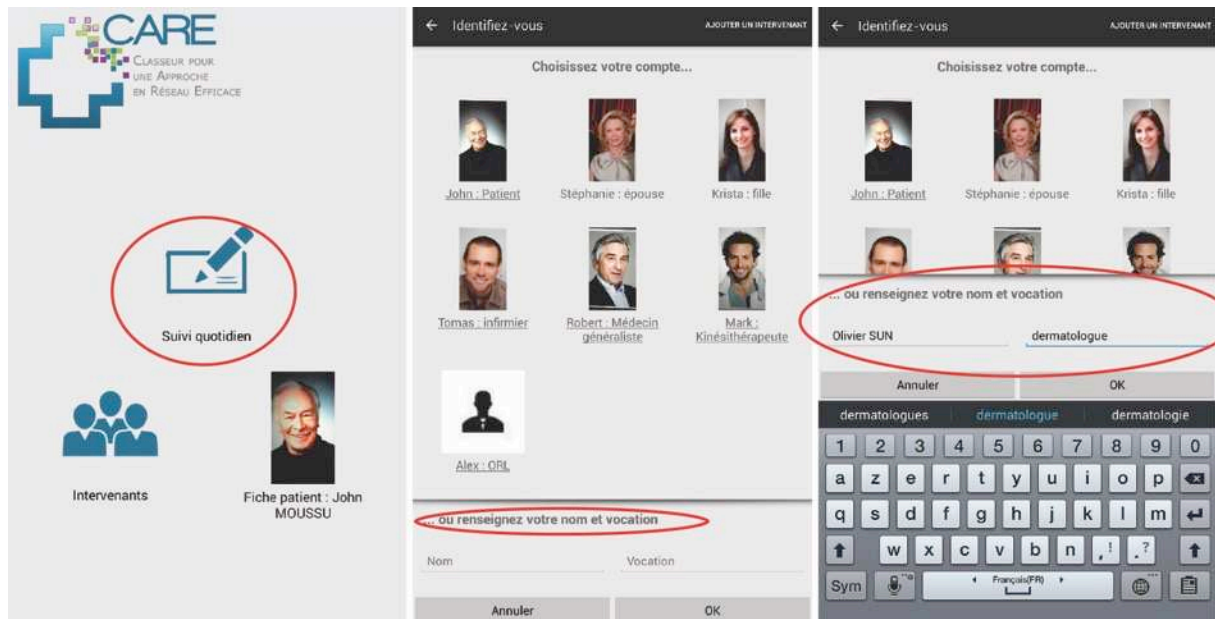
Figure 37- Adding a new drug

#### 4.4.4 Visit to the dermatologist

To help John recovering after having a fall a physiotherapist visits him twice a week. During his visit at home, the physiotherapist noted redness on John's arm; Alice reports that he has been itching for two days. The physiotherapist calls the general practitioner to report the situation, and they decide to ask the opinion of a dermatologist, so the general practitioner organizes an appointment for John in two days.

After two days, John and Alice go to the dermatologist, taking the CARE tablet with them. After examining the patient, the dermatologist suspects that John has an allergic reaction, so he asks Alice if John has a new diet or is under a new medication. Alice gives the tablet to the doctor explaining to him that he can find the whole list of medication in it.

The dermatologist starts CARE and tries to access the "Suivi quotidien". As he does not have a profile, he enters his name and profession to access the application (Figure 38).



**Figure 38- Access of one-time care actor**

The dermatologist can see the messages exchanged between the different care actors. He looks at the message of the physiotherapist in which the observation of the redness on the arms of the patient is described and illustrated with a photo (Figure 39).





**Figure 39- The message of the physiotherapist**

Next, the doctor presses on the “médicament” (medicine) button to see the list of medication. The doctor realizes that the patient has a new medication that might be the cause of his allergy.

Before writing his prescription, the dermatologist presses on the “patient” tab to see the patient’s profile, looking for more information about the patient’s condition.

The information let by the other care actors give the dermatologist an idea about the source of the problem encountered by the patient. The photo taken by the physiotherapist also allows him to notice the evolution of the problem.

Finally, the dermatologist prescribes some creams for the patient, writes a message to inform the other care actors about his diagnosis and proposes to replace one of the medications by another one.

SUIVI QUOTIDIEN
DISCUSSIONS
INTERVENANTS
PATIENT

adventicium nini inveniretur, teneta ora manilla in  
Lycaoniam Telephone : 03334457

---

**Taille** :1.65 m **IMC** :23,51

**Poids** :64.0 kg

**Groupe sanguin** :O Rh +

**Antécédents**

Antécédents médicaux et fractures de risque

Hypertension artérielle(1975)

Hypercholestérolémie(1983)

Diabète de type 2

...

MARS 2015

LUN.	MAR.	MER.	JEU.	VEN.	SAM.	DIM.
23	24	25	26	27	28	1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29
30	31	1	2	3	4	5

Indicateurs Biologiques

Noté par	Indicateurs Biologiques	Date	Heure
Tomas	1,40 g/l	27/03/2015	22:52
Tomas	LDL cholestherol: 1.60g/l	27/03/2015	18:43

Constantes Physiologiques

Prise par	Information	Date	Heure
Tomas	T°38- TA 13/9- P 88	27/03/2015	18:43
Tomas	T°39- TA 19/9- P 188	27/03/2015	18:43
Tomas	T°37- TA 16/10- P 72	27/03/2015	18:43

**Figure 40: Patient's profile including the patient's medical antecedents, the visits of care actors marked in the calendar and tables with information tagged by the different care actors**

## 4.5 CARE PILOT STUDY

Our research approach is aligned with the two steps living lab approach described in (Budweg et al. 2012); the authors propose coupling semi-realistic lab environment to explore and validate concrete ideas as well as more abstract basic research issues in the early stages of a project, with evaluation in real households over a long-term period. So our pilot study was conducted as a second step investigation, after the first assessment of the CARE application during two design workshops (presented in section 3.2.1). The feedback that we collected during these workshops was integrated into the working prototype (presented earlier in this chapter in section 4.3), and we then rolled out the CARE prototype in the homes of five patients.

Adopting a summative perspective (Scriven, 1967), our main focus was to look whether the CARE application supports the collaboration between care actors and thus, participates in the sustainability of their collaborative practices (knotworking).

In the following, we first describe the recruitment process of our participants. Next, we present the roll out of the CARE application in the home of the patients and how we introduced the application to all the participants. We then describe the different kinds of data collected through the pilot study. Finally, we report on our findings based on the analysis of the collected data.

### **Method**

The pilot study lasted 20 weeks (01/07/2015- 30/11/2015). We equipped five households with tablets. The patients, their family caregivers, and all their care actors were allowed to use the tablets left in the homes of the patients.

#### *4.5.1.1 Finding candidates and inclusion criteria*

As we are interested in supporting the collaboration between evolving team members, the question of knowing in advance all the included care actors that might use our application was challenging. Thus, to recruit candidates, we organized a presentation of the CARE application with the help of e-maison médicale. The invitation to this presentation was sent to care actors working in Troyes (and not only to the members of e-maison médicale). More than thirty participants, covering a wide range of health and care actors, attended this presentation: general practitioners, specialists, pharmacists, physiotherapists, nurses, professional caregivers, and home helpers. Some participants were also representing other organizations working in home care provision: the hospital at home service (HAD, hospitalisation à domicile) and the newly created association of self-employed home helpers (AVA<sup>12</sup>). Finally, the head of the emergency service of the Troyes Hospital also attended.

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<sup>12</sup> AVA stands for (AUXILIAIRES DE VIE AUBOISES)

This presentation was covered by two local newspapers, which contributed, in our opinion, in facilitating the participation of people who did not assist the presentation. Presenting the application to this large audience gave us first interesting feedback that we will mention later on.

During the presentation, we collected the contacts of the care actors who were interested in participating in our deployment. The week after, we organized a discussion session with interested care actors who came with patients' profiles in order to decide which patients will participate in the pilot study.

We included five patients: four proposed by general practitioners and one patient proposed by a registered nurse. We decided to include people with complex situations maintained at home thanks to the intervention of multiple care actors. We also tried to include patients with different care profiles. For example, we recruited two patients managed mainly by the members of e-maison médicale, two for which e-maison médicale members shared the management of the patient situation with other independent care actors, and finally one managed entirely by independent care actors.

**Table 5: Patients participating in the pilot study<sup>13</sup>**

Patient	Age	Number of professional care actors	Number of family caregivers	Comments
Mrs. SC	81	4	0	Only the nurse is a member of e-maison médicale
Mr. SS	73	6	0	Mainly taking care of by members of e-maison médicale
Mr. AA	75	6	5	Only the GP is part of the e-maison médicale
Mr. DR	80	4	1	Only the GP is part of the e-maison médicale
Mrs. KI	65	5	0	Completely managed by members of e-maison médicale

#### 4.5.1.2 Rolling out CARE

The first time we went to the home of the patients and met patients and/or family members, we came with the tablet and a printed guide. The duration of our visit was between sixty and ninety minutes, during which we explained the objective of the pilot study, and we created together the different profiles who were going to access CARE on the tablet. All the participants provided informed consent, indicating their agreement to participate in the pilot study (the form is presented in annex 1).

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<sup>13</sup> The number of the professional care actors includes only the main ones and do not count for the colleagues who work with the patient in case of the absence of the main professional care actor.

During the same first visit, we tried to make a list of the care actors of the patients in order to be able to contact them. We tried to fix an appointment with each of them for training them, usually at the home of the patient during their routine visits.

This second visit for training a care actor lasted between twenty and thirty minutes. During this visit, we showed the care actor how to create his/her profile and how to find information and write messages.

We also left a poster in each home that was indicating that the patient is participating in the pilot study and that all the care actors who are taking care of him/her are invited to participate (Figure 41). We also left a paper-based guide explaining all the features of the application along with our contact information for any questions.



**Figure 41: The poster put on a cupboard in the house of one of the patients**

#### *4.5.1.3 Follow-up and data collection*

We collected data during and after the pilot study through regular visits at the patients' homes, and a discussion meeting with the involved care actors at the end of the study.

The visits at the patients' homes were defined during the first visit: we fixed a weekly visit for the first two months. Once the patient and the care actors were comfortable with the application, we reduced the visit to twice a month. During our visits, we checked if there was any technical problem or any questions about the application. We sometimes used the application together with the patient for writing a message for the other care actors for instance. These follow-up visits lasted between thirty and ninety minutes each time. At these occasions, we frequently met care actors doing their routine visits. They often had questions about the features of the application, and sometimes

had some suggestions. These regular visits also offered us the opportunity to talk with new care actors about CARE.

During these visits, we were taking notes, pictures, and a copy of the messages that were put into the application. The data were analyzed over the course of the study, which enabled us to ask more pertinent questions during our following visits.

We finally organized a discussion session with four of the care actors who participated in the field study (a general practitioner, a nurse, and two professional caregivers). They were members of e-maison médicale, and were using paper-based liaison notebooks at the homes of their patients for years. Three of them already participated into the workshops we organized during the design phase and were thus familiar with the application. The session lasted about three hours and allowed us to get feedback about their experience when using the application. It also offered the opportunity for the different actors to discuss their views on the use of a device compared to the paper-based notebook.

We also picked some data collected from different patients' tablets in order to ask the professionals some help in understanding the content. This session was video-recorded, and we took notes and photos.

This discussion session shaped our analysis of the whole data collected during this pilot study.

#### **4.5.2 The involvement of the patients and family members**

All the patients participating in our study were aged 65+. They were mainly anxious about their involvement in learning a new technology. Thus, though some patients were active in their care because they lived alone, all the patients were convinced that they have nothing to do with a tool that appeared for them as a tool for the health professionals.

For example, Mrs. SC who lives alone and suffers from anxiety problems along with many other conditions was very anxious about the idea of keeping the tablet at home. After explaining and discussing that with her, she accepted the idea but she refused to use the tablet.

*Mrs. SC (patient) "I do not like that [referring to technologies on general] ... then I do not feel ready, I have many things to do [...] at my age I prefer relaxing, I'm always tired ... Anyway with my osteoarthritis problems it is not easy to use it [referring to the tablet]"*

The care actors of Mrs. SC saw in the introducing the technology for her an opportunity to write about her stress problems. It took us multiple visits to gain her acceptance, and to be able to show her how to unlock the tablet and access the application. In fact, her osteoarthritis affects the joints of her fingers and makes it difficult for her to use the touchscreen of the tablet.

For Mr. SS, the situation was quite different. He liked the idea to have the tablet at home and was proud to participate in the pilot study. During each visit, we used the tablet together to look at the existing messages, and left messages for the other actors. For example, the nurse left a message pointing at the fact that Mr. SS had a fall at 7 am, so Mr. SS explained to me how it happened and how he called the nurse to help him. Mr. SS was thankful to the nurse so we commented on the nurse message, thanking him (Figure 42).



**Figure 42: Message from the patient thanking the nurse**

Family members had different attitudes towards the CARE application.

For example, Mrs. DR, the main family caregiver for her husband suffering from Alzheimer's disease (mentioned before in the section 3.3.1) was feeling overwhelmed by all the caregiving tasks and she then considered participating in the pilot study as an additional work for her.

*Mrs. DR (wife): "I don't have the time for that, I need to focus on taking care of my husband, I don't want to be rude... but I don't want any additional work or visits"*

In the case of Mr. AA, on the contrary, multiple family caregivers participate in caring activities. When introduced the first time to the oldest son of Mr. AA (aged 47), he explained to us that he never used a smartphone and that he saw the tablet (that we left at the home of Mr. AA) but he did not dare to use it. After showing him how to use the tablet, he was able to create his profile and created a first message.

After one month during which only the oldest son used CARE, all the five family members created their profiles. Three of them participated in writing messages and commenting the messages of the care professionals. The family members also used CARE to exchange messages among them and with other care actors, mainly to handle logistic issues. For example, the son of Mr. AA discussed with the professional caregiver about the new checkbook of Mr. AA (Figure 43).



Figure 43: Conversation about the new checkbook of Mr. AA

#### 4.5.3 The CARE application in use

During the pilot study, a variety of care actors used the CARE application, including family members, home helpers, professional caregivers, health professionals and social workers.

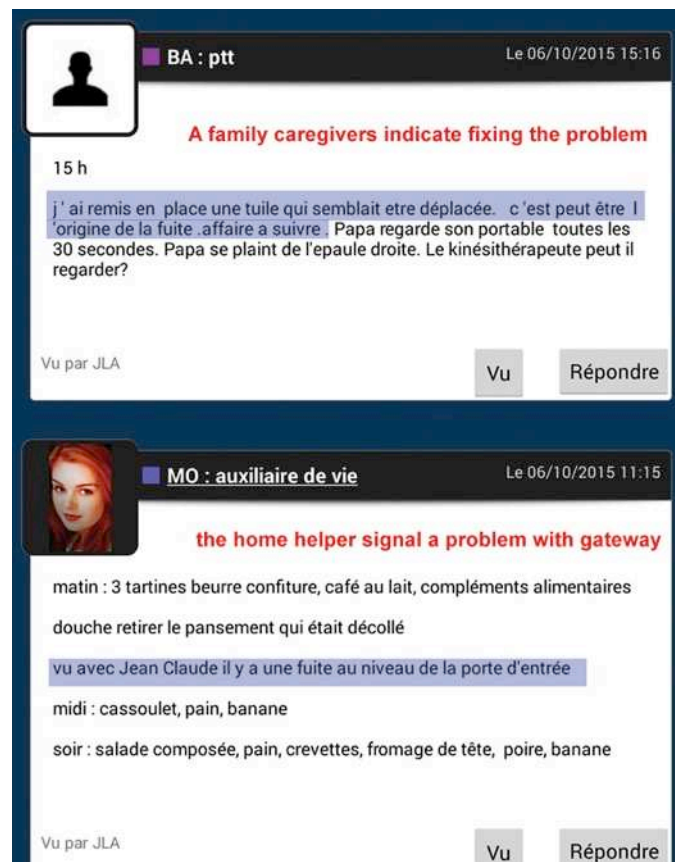
Every general practitioner created the profile of the patient his was taking care of. Many care actors created their own accounts and started using CARE without our help. During our weekly visits, we noticed an increasing number of profiles. The table shows the increasing numbers of the accounts created on the application of each patient.



Patients	Accounts on the application after one month		Accounts on the application after five months	
	Number of profiles	Number of messages	Number of profiles	Number of messages
Mrs. SC	3	10	4	56
Mr. SS	5	20	11	129
Mr. AA	6	37	15	227
Mr. DR	3	3	-	-
Mrs. KI	4	10	5	105

**Table 6: The account of care actors during the pilot study**

The different actors exchanged messages about the situation of the patient, their daily tasks, asked questions and addressed issues beyond the medical condition of the patient. We can see for example a message exchanged between one family member and the home helper about the problem of water that is leaking in through the exterior door (Figure 44).



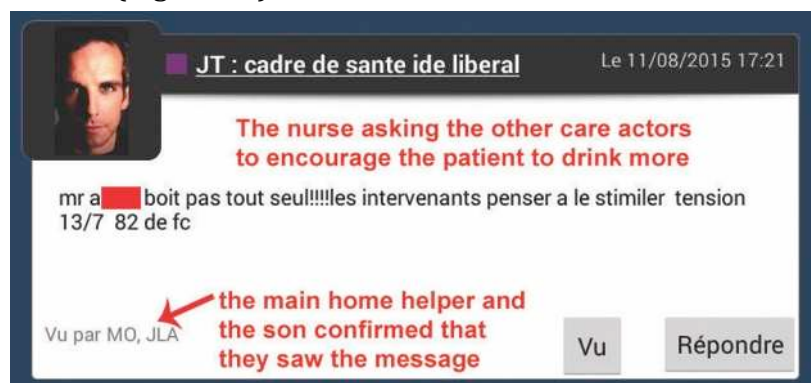
**Figure 44: Messages exchanged between the home helper and a family member**

Most of the messages are short and most of the content could not be understood without reading the previous messages. For the care actors involved in the patient care, it is easy to identify the relevant information and to understand what the other care actors are conveying in their messages.

*MO (home helper): "When you read the messages every day you end up by having a pretty good idea of what is going on. Also, we are at the home we can see what they are talking about."*

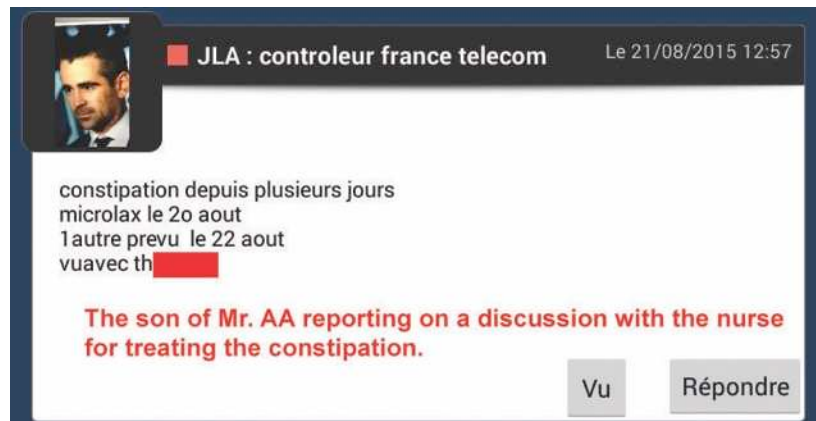
All the care actors wrote messages that report their activity, signal a problem, or give instructions; yet, their participation (in terms of number of messages and the type of information documented) varies, according to their profile:

- Home helpers who are used to write down their activities on a paper-based document (a notebook, a binder, or notes) easily changed the media to document all their activities on the application. For example, in Figure 44 the home helper lists in her message all the caring activities and meals prepared for the patient during her three visits that day.
- Family members mainly used the application for communicating and addressing issues, more than reporting.
- Health professionals wrote shorter messages (often only one sentence). They reported on their activity with numbers, which are difficult for non-health professionals to understand. However, when there was a problem, they completed the numbers with some text explaining the problem or giving instructions. For example, after examining the patient's blood pressure, this care professional gives some instruction about the patient who needs to drink more water (Figure 45).



**Figure 45: Message from the nurse**

- Finally, sometimes, family members or home helpers included in their messages some information coming from the doctor or the nurse (Figure 46).



**Figure 46: Reporting on the discussion with the nurse**

According to the patient's conditions, the kind of problems that were addressed differed; when the situation of the patient is stable, the care actors mainly focus on logistics issues. However, when a medical issue arose, CARE was used for reporting on the solution (Figure 46), and the issues were addressed through more direct communication like phone call or a consultation.

#### **4.5.4 Analysis**

Using the CARE application as a “technology probe” (Hutchinson et al. 2003) to gain different insight into how the work is done and how technologies might support the collaborative practices, the pilot study allowed us to better understand the complexity of keeping the patient safe at home.

We adopted a general inductive approach (Thomas 2006) for analyzing the data collected during and after the pilot study. We identified three themes related to supporting knotworking, which are: ensuring flexibility to accommodate different values, building trust, and open sharing. These themes are obviously interrelated: the flexibility allows the participation of a wild range of actors, which is essential for knotworking as it increases the chances of detecting issues and addressing complex issues collectively. The participation enabled by the flexibility facilitates creating a certain level of trust that is required for open sharing. Finally, open sharing allows care actors to identify issues that might trigger knots.

##### *4.5.4.1 Flexibility to accommodate different values*

The care actors share the conviction that their collaboration is necessary when they want to keep a patient with complex situation at home. However, the care actors have different perceptions of the effort that is necessary to achieve this collective management of care. This idea can be illustrated by looking at the different perceptions of time among the care actors: five minutes might be perceived as a short period for a home helper or a family member, but it might represent a full visit for a nurse.

This different perception of time is reflected in the diverging opinions about the efficacy of using the CARE application. Consequently, the health professionals like the nurse and the general practitioner found the application more difficult to deal with than a paper-based notebook.

The nurse stated that using the tablet takes a lot of time. According to him, the notebook offers a good visibility on what happened in the last two days with a glance thanks to the double pages view. The general practitioner mentioned that the uniformity of the messages makes the important messages and the less important ones look alike. According to him, the paper-based notebook permits to change the style of the wording and gives him indication about the important messages. In the same way, the nurse regretted to not be able to integrate some drawings directly in the message, because he said that it could save time when explaining complex issues.

On the contrary, home-helpers were much more positive about CARE. They were aware of the time needed to learn how to use the application, but they stated that once they were familiar with it, the application gave them more visibility on what was going on around the patient.

The perception of time is related to the conviction of the care actor that an effort is worth the time. In fact, even among health professionals, we have found this variation. For example, some doctors took all the necessary time to add a full list of the medications and completed the profile of their patient and others did not. Thus, some doctors were convinced that filling the profiles of certain patients is worthwhile and other did not.

In our understanding, the home-helpers were more motivated to use CARE because it acknowledged that they were part of the care ensemble. It gave them additional recognition of their irreplaceable role in keeping the patient safe at home. The necessary motivation to overcome the learning period was provided by this recognition.

In summary, when care actors are involved in knotworking, acknowledging their different values and perceptions becomes key to sustain their participation. The collective management of the patient occurs thanks to the care actors, thus, ignoring that they have different perceptions of some notions like time might affect their motivation and hinder their collaboration. A system supporting knotworking has to be flexible enough to accommodate the different needs of the wide range of actors. In our case, it means for example, offering health care actors a way to scan other care actors participations in a short time and helping them to identify when there is something that needs their attention (like an alert) or intervention (like a question or demand). The difficulty resides in creating systems that adapt to the different potential users. One way to tackle this issue is to use the traces of their interaction as described in (Curé, Prié, and Champin 2012) where is propose to augment an application with a framework for managing the traces of interaction in order to enhance the user experience through detecting repetitive operations and thus enabling the system to offer making changes based on the trace reasoning.

#### 4.5.4.2 Building Trust

*« Il n'y a pas de médecine sans confiance, de confiance sans confiance et de confiance sans secret », Professeur Louis PORTES*

Our work with the patients highlighted the central role of trust when it comes to home care. This trust comes from different sources, like for instance the fact that the care actor belongs to a respectful institution (this is especially the case for home-helpers), or the respect of the skills of doctors or nurses. Another source might be to trust a care actor based on a friend or a family member recommendation. It is rare, to keep a care actor when his/her work or attitude is not satisfying. This might be a particularity of the French primary sector but it is important to mention it to understand how issues such as sharing medical information, occur in this context.

The current care actors played an important role in introducing us to the different patients. Thanks to the trustful relationship that existed between the patient and the different care actors, we were accepted as an extension of the care process.

However, using CARE as a tool for sharing information between all the care actors (including the patient and the family members) was problematic, particularly for elderly patients. As we mentioned before (in section 4.5.2), people were anxious about the introduction of technology that they do not control, and it was also true for some of the professionals. For example, one of the general practitioners was skeptical about participating in the pilot study because he thought it was illegal to write about the patient's medical situation. After we explained him that the information is stored locally on the tablet of the patient, he accepted to participate in the experiment and signed the informed consent. However, he did not create his profile. In our opinion, the general practitioner had a double problem of trust, both towards the technology and with us as he identified us as part of the e-maison médicale association<sup>14</sup>.

In the collective management of the patient's situation, the different care actors share, though not officially, the responsibility of the patient. Thus, care actors trust each other to start this voluntary collaboration. They share information and delegate tasks and count on each other support when there is a problem.

This is reflected in the different ways the care actors used CARE. For some patients, like Mr. AA and Mr. SS, CARE was used to facilitate the collaboration. The care actors exchanged messages and addressed issues using the application. Most of the new care actors created their profiles and started to participate in the discussions. Most of the care actors who did not really meet before were able to be introduced to each other and to exchange messages about the patient through the application.

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<sup>14</sup> Here we want to precise that some self-employed (liberal) care actors of the city of Troyes are not aligned with the collaborative care practices of e-maison médicale and question them; these practices, as we explain in (section 3.1), represent an innovative (and disturbing) approach of home care, at least in France.

However, for other patients, the application was used only to keep basic information like in the case of Mrs. KI where the professional care actors organized their work but avoided documenting information on the tablet or on a notebook to protect the patient's privacy as she had juridical problem with family members in the past<sup>15</sup>. In the case of Mrs. SC., the general practitioner was completely absent from the application due the issue of trust as we explained earlier. Finally, the experiment was interrupted and the application was totally rejected by the main family caregiver (the wife) in the case of Mr. DR.

In summary, we argue that trust plays a major role in organizing work and collaboration in home care. We suggest that an application supporting collaboration between care actors who meet rarely has to enable trust building between the different care actors. In our case, the application participated in introducing different care actors to each other and offered a place to start discussion between the care actors. We believe that this provided the first step towards building trust and extending current collaboration.

#### *4.5.4.3 Open sharing*

The CARE application offers a place for sharing information where care actors decide what and how to document. The application provides some categories for organizing information (e.g. medications, or test results) but it is up to the care actors to use them.

Sharing information about the patient is essential for the collaboration between the care actors. As we discussed in chapter 3, sharing the different views on the care problems in the form of discussions triggers the emergence of knots. Thus, to collaborate, care actors need to share medical and non-medical information about the patient, which might be problematic because not all the care actors have the right to read medical information. This situation raised a lot of questions and discussions about the viability of technological solutions that offer open sharing to facilitate collaboration in the medical context.

Keeping all kind of medical information seems to be unrealistic and sometimes dangerous in the context of caring of patients with complex conditions. Health professional were skeptical about writing information related to the patient's medical situation on the tablet. In fact, the home care actors, particularly the members of e-maison médicale, already share medical information on the paper-based liaison notebooks. They consider this information as a "shared secret". According to the article N° L1110-4 of the French public health code the "shared secret" is made available either for health professionals to ensure the continuity of health care or inside institutions where the patient is taking care of by a team like in a "Health care center<sup>16</sup>" or a "Home

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<sup>15</sup> The problems started after starting the experiment, the case of the patient was interesting as only managed by the members of e-maison médicale.

<sup>16</sup> Selon le code de la santé publique - Article L6323-1 "Les centres de santé sont des structures sanitaires de proximité dispensant principalement des soins de premier recours. Ils assurent des activités de soins

of care<sup>17</sup>". Thus, the home care actor we met extends the notion of the shared secret because they trust each other and they feel able to control the diffusion of the information by using the paper-based liaison notebooks. Here, we have to mention that the public health code is more explicit about sharing medical information through electronic transmission.

*"To ensure the confidentiality of medical information [...], the storage of this information in computerized formats, as well as their electronic transmission between professionals, is subject to rules established by decree of the State Council issued after public notice and the Commission's reasoned national data Processing and liberties. This decree determines where the use of the health professional card [...] or equivalent device [...] is mandatory. Health professional card and the approved equivalent devices are used by health professionals, health care facilities, health networks or any other body involved in the prevention and care." article N° L1110-4 of the public health code*

Despite the restrictions of the regulation, the care actors adopted CARE as an augmented version of the liaison notebook. The fact that the information is stored locally on the tablet of the patient might have played a role in their acceptance.

When opting for open sharing, we made the assumption that the care actors knew what was the information that was possible to share. For example, though the application offers a place to add the current medication of the patient, it is left to the general practitioner to decide if it necessary to fill it. This is completely different to a medical Information System in which medication would be automatically added to the list when prescribed or when the medicine is bought at the pharmacy.

However, some care actors mentioned that predefined categories of information might indicate what kind of information should be documented and thus enhance the usefulness of such application.

Open sharing allowed the different care actors to feel concerned by documenting the information and reading the information written by other care actors. Members of e-maison médicale used the tablet as an augmented version of the liaison notebook; other

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sans hébergement, au centre ou au domicile du patient, [...] et mènent des actions de santé publique, de prévention, d'éducation pour la santé et des actions sociales [...]. Ils peuvent mener des actions d'éducation thérapeutique des patients. Ils peuvent pratiquer des interruptions volontaires de grossesse dans les conditions prévues aux articles L. 2212-1 à L. 2212-10 du présent code, selon des modalités définies par un cahier des charges établi par la Haute Autorité de santé, dans le cadre d'une convention conclue au titre de l'article L. 2212-2.

<sup>17</sup> Selon le code de la santé publique - Article L6323-3 La maison de santé est une personne morale constituée entre des professionnels médicaux, auxiliaires médicaux ou pharmaciens. Ces professionnels assurent des activités de soins sans hébergement de premier recours au sens de l'article L. 1411-11 et, le cas échéant, de second recours au sens de l'article L. 1411-12 et peuvent participer à des actions de santé publique, de prévention, d'éducation pour la santé et à des actions sociales dans le cadre du projet de santé qu'ils élaborent et dans le respect d'un cahier des charges déterminé par arrêté du ministre chargé de la santé.

care actors who documented their transmission notebooks (like for home helpers) or did not read or share information with other care actors used the application first by curiosity, and then to communicate with other care actors.

In summary, open sharing is required when care actors collaborate in form of knots because care actors have to be aware of each other views to identify issues that require to be addressed collectively. However, open sharing in the context of home care raises the questions of the reliability and the confidentiality of shared information.

#### *4.5.4.4 Notes on the implementation and the training*

About 60% of the 45 regular care actors of e-maison médicale adopted the application and integrated it into their practices. Over the time, the involvement of the people increased, as we illustrated above in Table 6.

However, some features of CARE were not used, and the main features that were used were the creation of a new profile and the exchange of messages.

For some of the care actors, it was difficult to see how features like tagging could provide an answer to their needs, even though they participated in the design process and in collective presentations. For example, during the discussion session organized after the pilot study, the nurse and the general practitioner were suggesting a feature to enhance the identification of important information and the navigation in the data, even if these elements were already supported by the application. While we avoided defending the application, the two home-helpers were actively demonstrating that these features already exist in the application.

Thus, the participation of the care actors in the design process, although insightful, had little if any effect on the way care actors appropriated the application. In fact, the nurse and the general practitioner who initiated the project and were present in the two design workshops and which propositions shaped the application features were the most critical about these features during the pilot study. However, the care actors who had the chance to spend more time using the application identified better the different possibilities that the application was offering.

According to the above-mentioned nurse, they still need more training, not only about using the application but also about learning a common synthesized language that would be shared among the different care actors. This, in his opinion, would help to document complex issues with less time on the tablet.





## **5 CONCLUSION**

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The study was set out to investigate collaboration that occurs between people involved in a knotworking process. The study has also sought to know how to design technologies to support collaboration in a knotworking process.

Knotworking describes a way of organizing work and collaboration in which members of the collaborative ensemble form improvised combination of people to address the changing requirement (Engeström, Engeström, and Vähäaho 1999). The knotworking flourishes in a dynamic context in which actors have to re-configure their organization to accommodate the changing objective. Thus, knotworking provides a way to tackle the complexity of interactions.

*“Knotworking is not reducible to a single knot, or a single episode. It is a temporal trajectory of successive, task-orientated combinations of people and artefacts ...fragile because they rely on fast accomplishment of intersubjective understanding, distributed control and co-ordinated action between actors who otherwise have relatively little to do with each other ...In knotworking, the combinations of people and the contents of tasks change constantly.” (Engeström, Engeström, and Vähäaho 1999, 352–353).*

The CSCW literature on this subject and specifically in the context of home care gives insights to address the complexity of supporting collaboration between the different actors, but does not specifically addresses the collaboration like it takes place in knotworking (Table 7). To better support this collaboration our study sought to answer two questions:

- 1- How collaboration occurs in a knotworking process?
- 2- How can we computer-support the knotworking process?

Our work provides a case study in the home care context through which we have identified the main characteristics of knotworking, the reasons and motivation for knotworking, and the challenges people involved in knotworking face. Based on our findings, we suggested design principles (section 4.1) that we implemented in our proposed socio-technical solution (chapter 4). Finally, we conducted a pilot study for 20 weeks (section 4.5) that aimed at propping our results. It gave us further insights on how to design technology to support collaboration in knotworking. In the following, we synthesize our main empirical findings and their implications, and we conclude by highlighting some limitations of the study and future work.

## 5.1 FINDINGS

The main empirical findings were summarized in the chapter three in the section 3.3 and chapter four in the section 4.5.4. In this section, we combine the empirical findings to answer our research questions.

### 1- How collaboration occurs in knotworking?

**a) *Sharing a complex objective in a dynamic context.*** Knotworking thrives in a dynamic context, in which a variety of actors collaborate to re-organize their work to accommodate an evolving objective. In the case we presented, the care actors share the objective of preserving the quality of life of the patient at home. The different care actors have to address issues spanning medical, social and logistic aspects of care, which, depending on the situation of the patient, requires the collaboration of a diverse set of people.

The evolution of the patient's situation and the emerging issues determine who will be involved in a collaborative episode.

**b) *Creating a place to exchange around the objective.*** People involved in knotworking have to be aware of the emerging issues that hinder achieving the objective. We have seen that the care actors use the liaison notebook to exchange information about the patient situation, to stay aware of each other's activities, and to coordinate the care. The liaison notebook reflects the status of the patient, including issues that trigger the creation of knots. Thus, the liaison notebook plays the role of a central place for the care actors to exchange, be aware of problems, and participate in the definition and implementation of the solution.

This central artifact represents the place where all the care actors can share their perspective on the situation of the patient and the care activities. This space allows new care actors to have an idea of the current work organization and allows them to share their perspective.

**c) *Adopting a flexible organization to cope with the changing objective.*** The knotworking process accommodates the evolving objective by grouping necessary people to address emerging issues. This temporary collaborative episodes might create new collaborative practices between otherwise loosely connected members of the cooperative ensemble. The results of such collaborative episodes are evolution in the organization of work. In our case, the care actors follow two different rhythms to address different issues affecting the quality of life of the patient. In the standard rhythm, the care actors organize their work according to the care plan, which is a verbal agreement about what care actors should do to keep the patient safe at home. However, when the quality of life of the patient is jeopardized due to the evolution of his/her status or an emerging issue, the care actors adopt an intense collaborative rhythm. It implies intensive communication taking place asynchronously or face-to-face. The

intensive collaboration might lead to changes in the care plan, including extending the current collaborative ensemble i.e. asking for the participation of new care actors.

## **2- How to design for supporting knotworking**

To support knotworking one has to consider:

### ***a) Flexibility to take into account diverse perspectives.***

When the care actors are involved in knotworking, acknowledging their different values and perceptions becomes key to sustain their participation. The collective management of the patient occurs thanks to the motivation of the care actors. Thus, ignoring that they have different perceptions of time for instance might affect their motivation and hinder the collaboration. A system supporting knotworking has to be flexible enough to accommodate the different needs of the wide range of actors. In our case, it means for example, offering the care actors a way to easily scan the participations of the other care actors and helping them to identify when there is something that needs their attention (like an alert) or intervention (like a question or demand).

### ***b) Building trust by enabling the communication between the members of the cooperative ensemble.***

Trust plays an important role in organizing work in the home care domain. We suggest that an application supporting collaboration between care actors who meet rarely has to enable trust building between the different care actors. In our case, the application participated in introducing different care actors to each other and offered a place to start discussion between them. We believe that this provided the first step towards building trust and extending current collaboration.

### ***C) Creating a place for open sharing to address emerging issues***

Through the knotworking process the involved actors cannot predict what will be the necessary information to document or to find. But sharing information about the situation of the patient is essential for the collaboration between the care actors. As we mentioned earlier in chapter 3, sharing the different views on the care problems in the form of discussions triggers the emergence of knots. Thus, a system for knotworking should offer a place to share the information openly without predefined categories, and should allow the involved care actors to index what they consider as important information.

## 5.2 IMPLICATIONS

### 5.2.1 *Conceptual implications*

Considering knotworking from a CSCW perspective offers a better understanding of the complexity of supporting collaboration in such a context. The CSCW literature provides a wide set of concepts that helped us to describe how collaboration occurs in knotworking, as a step towards developing supporting technologies. For example, the concept of coordination mechanisms (Schmidt and Simone 1996) provides an interesting framework to analyze collaboration in knotworking.

*"A coordination mechanism is a construct consisting of a coordinative protocol (an integrated set of procedures and conventions stipulating the articulation of interdependent distributed activities) on the one hand and on the other hand an artifact (a permanent symbolic construct) in which the protocol is objectified." (Schmidt and Simone 1996, 165–166)*

However, as we discussed in chapter 2, the coordination mechanisms was originally defined for relatively stable work settings. In cooperative work settings such as the one we introduced in chapter 3, the description of the coordination mechanisms has to be more dynamic to cope with its contingencies. Thus, the notion of coordinative protocol has to be revisited to reflect the episodic changes that the protocol will eventually undertake.

This study shows that further investigation is required to address how to support collaboration in knotworking (Table 7). Thus, we see our work as an invitation for CSCW researchers to go on investigating this kind of collaboration.

Furthermore, knotworking offers interesting insights to understand how to support collaboration in a dynamic context, particularly in home care. The existing cases of collaboration in home care might therefore be revisited in order to offer more sustainable home care services.

### 5.2.2 *Policy implication*

Our fieldwork highlighted the importance of sharing information among the different care actors to ensure the quality of care. Designing technologies to support collaboration in home care is hindered by a lack of adequate policy for sharing information. We claim that extending the notion of “shared secret”<sup>18</sup> to include care actors at home might be a first step. We also propose that the patients or their family should be able to identify who is involved in the home care and thus, who should have the right to access the shared information.

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<sup>18</sup> The notion is proposed in According to the article N° L1110-4 of the French public health code and we discussed the notion in section 4.5.43

	<b>Insights from the CSCW literature</b>	
<b>Characteristics of knotworking</b>	<b>Concepts</b>	<b>The case of collaboration in home care</b>
<p>The collaborative ensemble is not a priori defined and is constantly evolving</p> <p>The work arrangements are not defined and not predictable</p>	<ul style="list-style-type: none"> <li>- Boundary objects</li> <li>- Coordination mechanisms</li> <li>- Common Information Space (CIS)</li> </ul>	<ul style="list-style-type: none"> <li>- Using monitoring to increase awareness of the patient's situation and adapt the care (Bardram, Bossen, and Thomsen 2005; Mamykina et al. 2008; Andersen et al. 2011).</li> <li>- Using electronic patient files (like EHR or PHR) to allow every stakeholders to take part in the communication around the patient (Hayes et al. 2011), (Reuss et al. 2004), (Hägglund et al. 2007), (Piras and Zanutto 2010).</li> <li>- Supporting the organization of care at home (Bossen et al. 2013)</li> <li>- CARE offers a place where new care actors can be introduced to the existing situation around the patient and can discuss their view on the patient care.</li> <li>- CARE offers a place where care actors can be aware of each other presence and activities.</li> <li>- CARE offers a place to highlight the change in the patient's situation and to adjust their practices.</li> </ul>
<p>Collaboration occurs in episodes</p>		<ul style="list-style-type: none"> <li>- CARE offers a place to reflect the evolution of the patient's situation to help care actors making pertinent decisions when issues emerge.</li> </ul>

**Table 7. Summary of the study contributions**

### 5.3 LIMITATION OF THE STUDY AND FUTURE RESEARCH

Working on a case study provided us the necessary empirical ground to observe and learn how collaboration occurs in knotworking in the context of home care. However, this approach comes with limitations related to generalization. Conducting more case studies in other contexts would be necessary to identify the results that are context-related and others that relate to collaboration in knotworking in general.

The patients that participated in our pilot study had a relative stable situation, which is of course good for the patients, and which is a sign of effective organization of care. However, it implies that we did not have the opportunity to observe any knot formation through the pilot study. Thus, we were not able to observe how our proposed solution might affect the formation of a knot.

Finally, we believe that the data analysis would have profited from multiple views. In fact, the data collection and analysis were done mainly by the same researcher, which we think influenced the analysis of data.

In terms of future work, we did not have the chance during the pilot study to test whether the indexing feature enhances the readability and facilitates the integration of new care actors. We would then like to focus on the potential of this indexation feature.

Finally, to further investigate the collaboration in knotworking, future research could focus on how to enhance trust building through communication. We think that the literature on social network at work offers an interesting start. Related questions include what motivates the use of social network at work (DiMicco et al. 2008) and the exploration of the different attitudes towards sharing information in such a context (Muller et al. 2010).





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## ANNEXS

### ANNEX1: INFORMED CONSENT

#### FORMULAIRE DE RECUEIL DE CONSENTEMENT ECLAIRE

*(Fait en 2 exemplaires : un exemplaire est remis à la personne, l'autre est conservé par l'investigateur)*

**Je soussigné:** M., Mme, Mlle

Nom : .....

Prénom : .....

Adresse : .....

.....

Déclare que :

J'ai reçu toutes les informations nécessaires pour comprendre l'intérêt et le déroulement de l'étude, les bénéfices attendus, les contraintes et les risques prévisibles s'ils existent.

J'ai pu poser toutes les questions nécessaires à la bonne compréhension de ces informations et j'ai reçu des réponses claires et précises.

J'ai disposé d'un délai de réflexion suffisant entre les informations reçues et ce consentement avant de prendre ma décision.

En foi de quoi, **J'accepte**, librement, et de façon éclairée, de participer comme sujet à l'étude intitulée : **PICADO – Projet Innovant pour le Changement d'Ampleur de la Domomédecine** dont le promoteur est L'Université de Technologie de Troyes (UTT), 12, rue Marie Curie BP. 2060, 10010 Troyes sous la direction de Myriam Lewkowicz.

#### **Principaux investigateurs :**

Khuloud Abou Amscha en sa qualité de doctorant.

Myriam Lewkowicz en sa qualité de responsable scientifique du projet pour l'équipe Tech-CICO de l'UTT, et directrice de la thèse de Khuloud Abou Amscha.

#### **But de l'étude :**

Ce travail de recherche s'inscrit dans le cadre du projet national PICADO<sup>19</sup> qui vise à concevoir, réaliser et valider le premier système opérationnel de domomédecine multi-pathologies (cancer, pathologies neurodégénératives, diabète). Le concept de "Domomédecine" a été proposé par l'Académie des Technologies en 2008 (Lévi & Saguez, 2008) et se définit comme l'ensemble des actes et soins, parfois complexes, dispensés au domicile du patient ou durant ses activités socioprofessionnelles, visant à privilégier son maintien à domicile ou en activité. Cette nouvelle forme de prise en charge nécessite la mise en place de technologies à la fois pour assurer un suivi global du patient à distance et pour permettre une bonne coordination entre l'ensemble des

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<sup>19</sup> Projet Innovant pour le Changement d'Ampleur de la Domomédecine

parties prenantes qui doivent intervenir pour prendre en charge le patient (personnel hospitalier, médecin traitant, infirmières de ville, pharmacien, éventuellement des professions paramédicales, et l'entourage du patient). Une démarche de conception et d'évaluation participative a été adoptée afin de définir l'intégration de nouvelles technologies et procédures pour le suivi médical et les soins de patients à domicile ou en maintien d'autonomie, la communication, l'intermédiation et l'archivage des données, cela afin de faire émerger un nouveau système opérationnel de santé multi-acteurs et multi-pathologies centré sur le patient et son médecin.

#### **Engagement du Participant :**

L'étude consiste pour «le participant volontaire» à tester l'application CARE (Classeur pour une Approche en Réseau Efficace) qui documente les informations nécessaires à la prise en charge collective du patient à domicile.

L'équipement nécessaire (une tablette) sera fourni et installé à domicile. Les investigateurs principaux seront chargés de recueillir le résultat des tests à domicile de manière continue. Des entretiens seront conduits avec le participant pour évaluer l'impact de l'application sur les pratiques de soins à domicile.

#### **Engagement des investigateurs principaux :**

En tant qu'investigateurs principaux, ils s'engagent à mener cette recherche selon les dispositions éthiques et déontologiques, à protéger l'intégrité physique, psychologique et sociale des personnes tout au long de la recherche et à assurer la confidentialité des informations recueillies. Ils s'engagent également à fournir aux participants tout le soutien nécessaire lié à la participation à cette recherche.

#### **Liberté du participant :**

Le consentement pour poursuivre la recherche peut être retiré à tout moment sans donner de raison et sans encourir aucune responsabilité ni conséquence. Les réponses aux questions ont un caractère facultatif et le défaut de réponse n'aura aucune conséquence pour le sujet.

#### **Information du participant :**

Le participant a la possibilité d'obtenir des informations supplémentaires concernant cette recherche auprès des investigateurs principaux, et ce dans les limites des contraintes du plan de recherche.

#### **Confidentialité des informations :**

Toutes les informations concernant les participants seront conservées de façon anonyme et confidentielle. Les données personnelles concernant le participant seront aussi rendues anonymes, avant d'être intégrées dans un rapport ou une publication scientifique.

#### **Informatisation des données :**

J'accepte le traitement informatisé des données personnelles en conformité avec les dispositions de la loi 78/17 du 6 janvier 1978 relative à l'informatique, aux fichiers et aux libertés, modifiée par la Loi n° 2004-801 du 6 août 2004 de la commission nationale de l'informatique et des libertés (CNIL), relative à la protection des personnes physiques à l'égard des traitements de données à caractère personnel. En particulier, j'ai noté que je pourrais exercer, à tout moment, un droit d'accès et de rectification de mes données personnelles.

**Déontologie et éthique :**

Le promoteur et l'investigateur principal s'engagent à préserver absolument la confidentialité et le secret professionnel pour toutes les informations concernant le participant (titre I, articles 1,3,5 et 6 et titre II, articles3, 9 et 20 du code de déontologie des psychologues, France).

**En cas de prise de photos ou de films :**

Je donne mon accord pour que des photos ou des films soient exploités à des fins scientifiques. et Prénom du Participant	Date et Lieu	Signature
Nom et Prénom de l'investigateur principal	Date et Lieu	Signature

# Khuloud ABOU AMSHA

Doctorat : Ingénierie Sociotechnique des Connaissances, des Réseaux  
et du Développement Durable

Année 2016

## Assister la collaboration dans une forme de travail particulière, le knotworking. Le cas du soin à domicile

Le « knotworking » représente une forme innovante d'organisation du travail dans laquelle la collaboration prend place sous la forme d'épisodes en fonction des besoins de la situation. Cela implique de multiples défis pour soutenir la collaboration, dus à la nature épisodique, improvisée et inter-organisationnelle de cette collaboration. Notre objectif dans cette thèse est de relever ces défis, au travers d'un cas d'étude sur les pratiques collaboratives d'un groupe de professionnels de santé libéraux prenant en charge des patients à domicile. Nos résultats montrent : 1) La centralité des artefacts de coordination ; 2) comment la focalisation sur la qualité de vie des patients amène les acteurs de la prise en charge à traiter de problèmes au-delà du périmètre médical ; 3) que les acteurs de santé passent par différents rythmes de collaboration en fonction de l'évolution de la situation de leur patient. Ces résultats nous ont permis de définir des principes de conception et de développer l'application CARE (Classeur pour une Approche en Réseau Efficace), accessible sur une tablette et restant au domicile du patient. Les retours montrent le rôle potentiel des technologies pour motiver la participation de nouveaux acteurs de santé, et pour la mise en place d'un espace partagé pour les différents participants de la prise en charge. Notre travail contribue à la recherche en TCAO en mettant l'accent sur un nouveau modèle d'organisation du travail (knotworking) et en proposant la première étude de cas de conception d'un outil pour assister la collaboration dans ce contexte.

Mots clés : travail collaboratif - soins à domicile - logiciels de groupe - communication et technologie.

## Supporting Collaboration in Knotworking - a Design Case Study in Home Care

The development of new modes of working raises new challenges for supporting collaboration. Knotworking represents an innovative way of organizing work where collaboration occurs in episodes depending on the requirement of the current situation. Supporting collaboration in knotworking presents multiple challenges due to the episodic, improvised, and cross-boundary nature of the collaboration. Our objective in this thesis is to tackle these challenges. Thus, we conducted a design case study investigating the collaborative practices of a group of self-employed care professionals organized as an association which take care of patients at home. The results show: 1) the centrality of the coordinative artifacts for sharing information and coordinating the work; 2) how focusing on patients' quality of life leads care actors to address issues beyond the medical scope; 3) how the care actors experience different rhythms of collaboration depending on the patient's situation. Based on these results, we defined some implications for design and developed the CARE application (Classeur pour une Approche en Réseau Efficace), which is accessible via a tablet and stays at the home of the patient. Feedback reveals the potential role of technologies in motivating the participation of new care actors, and in the creation of a shared place for diverse participants. Our work contributes to CSCW by bringing to focus a new model of organizing work named knotworking and by providing a first design case study aiming at supporting collaboration in this context.

Keywords: home care services - groupware (computer software) - communication and technology.

Thèse réalisée en partenariat entre :

