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Design guidelines based on two case studies from the healthcare domain in Europe

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In this paper, we compare two cases of collaboration within healthcare in two European countries, France and Denmark respectively. In each of these two cases, we conducted a design case study, and we found that collaboration is ad hoc, temporary, and shifting with regards to collaborators, aims, and processes. We argue for the relevance of knotworking and its analytic potential for investigating the kind of collaborative work we observed. We also argue that our two cases present a higher complexity level than how knotworking has previously been described in the literature. We describe complex knotworking as having three characteristics: 1) collaboration happens between a dynamic number of actors (who are usually loosely connected), 2) collaboration happens in episodes, and 3) cooperative work arrangements are constantly negotiated. Using the concept of complex knotworking for a comparative analysis of our two design solutions, we outline generic design guidelines for developing computer support to manage complex knotworking situations.

CCS CONCEPTS•Human-centered computing~Collaborative and social computing~Collaborative and social computing theory, concepts and paradigms~Computer supported cooperative work.

## **KEYWORDS**

Ad-hoc collaboration; healthcare; knotworking; design guidelines

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1. INTRODUCTION

Within healthcare, there is a strong push to establish continuity of care across the hitherto somewhat disconnected domains of primary care (general practitioner, homecare, etc.) and secondary care (hospitals, specialized treatment, etc.). Also, with growing numbers of both people with chronic conditions as well as older adults, there is an emphasis in many countries on providing care at home to keep expensive stays at hospitals and specialized facilities such as elderly homes down, as well as to enhance people's quality of life [10,14,28,46]. However, the provision of care and treatment at home requires new organizational setups and the development of adequate IT support for communication and collaboration [34]. This entails a new complexity where established divisions of work between, for example, hospitals, general practitioners, and home care providers break down, and new and less stable cooperative arrangements have to be worked out. For example, when an older woman taking care of her husband with dementia at home breaks her arm. She has to be x-rayed, the arm put into a cast, and additional home care must be provided within a short time so that she can remain at home without stays

at specialized care facilities. In this case, home care staff, the general practitioner, the x-ray facility, and the orthopedic surgeon should quickly organize an effective treatment trajectory. However, these actors might not know each other beforehand and should organize without such collaboration having previously been established.

In this paper, we compare two cases in two European countries in which the collaborative work is characterized by contingent fluctuations between the stability of cooperators and normal intensity of work, and unexpected and pressing situations, where cooperation between new actors has to be established immediately. Thus, we compare the work done at the CareFacility that supports discharged hospital patients to return to an active life at home in Denmark [12] and home care provision by the HomeCareAlliance in France [2].

The broader relevance of these cases of shifting and temporary collaborative work in healthcare relates to contemporary shifts in organizations and domains, where existing boundaries become more porous or are broken down. Nowadays, many work situations depend on ad-hoc collaborations across both organizational boundaries and formal roles. As our collaborations become more emergent, and it is less predictable with whom we must collaborate, there is a need to better understand such situations and design technology to support them. Contingent work, also known as precarious or gig work, where employment is relatively short and aimed at specific tasks or projects, has grown. Employees have to find new ways to navigate their precarious work life, while organizations have to handle the loss of expertise when employees move on and establish new organizational setups to enable collaboration between distributed entities [31,32].

While existing theories and concepts such as ad-hoc collaboration [20], and loosely coupled work [42] already have been proposed, in this paper, we rely on the concept of knotworking suggested by Engeström and colleagues [24]. We propose that the concept of knotworking is fruitful for understanding and analyzing this kind of collaborative work, which cannot rely on established work arrangements and routines to the same degree as with stable organizations such as hospitals, production plants, and bureaucracies. By comparing the two cases, we further show the concept's analytic relevance and potential, and argue that the challenge has moved from supporting knotworking to supporting complex knotworking. Such complex knotworking has three characteristics, we argue, and based on these we compare the two design solutions for the CareFacility and the HomeCareAlliance respectively, and we outline design implications for this kind of shifting and unstable cooperative work.

In the following, we start by reviewing existing work related to 1) collaboration in healthcare, 2) knotworking, and 3) existing computer-based solutions for ad-hoc collaboration in healthcare. We then present the two cases and their related design solutions. Next, we compare knotworking across the two cases, which allows us to characterize complex knotworking and propose design guidelines for computer-supporting knotworking, which we discuss before ending with a conclusion.

#### 2. RELATED WORK AND THEORY

In this section, we first present an outline of the evolution of work practices in healthcare towards integrated care and multidisciplinary teams, and then focus on the concept of knotworking, as a promising concept to describe the new form of collaborative work. Finally, we look at solutions that have been designed to support collaboration in healthcare.

#### 2.1. Collaboration in healthcare

Collaborative practice has become a core element in complex care situations needing multidisciplinary teams. It has been reflected in CSCW research conducted, for instance, in hospitals [33], in palliative care [36,49] nursing homes [19], and home care [4]. This attention to collaborative practices is also reflected in the evolution of the concepts and the education curricula in healthcare. In particular, CanMEDS, the educational framework for specialist physicians, defined by the Royal College of Physicians and Surgeons of Canada and adopted by dozens of countries on five continents, defines seven roles that lead to optimal health and health care outcomes: Medical expert (central role), communicator, collaborator, ACM CSCW 2021 Submission

manager, health advocate, scholar and professional. Regarding the collaborator role, it states that: "As collaborators, physicians work effectively with other health care professionals to provide safe, highquality, patient-centered care" [26:18]. Together with this vision of the physician acting as a collaborator, the concept of "interdisciplinary team" also emerged, as well as studies on how such teams function [39]. The centrality of collaboration in healthcare is also demonstrated by the interest in measuring it: In the USA for instance, an "Index of Interdisciplinary Collaboration" (IIC) has been defined to measure the perceived collaboration among social workers [13] and has since been adapted for collaboration among health professionals [39]. This has resulted in the identification of the following factors of a successful collaboration: interdependence between team members, the flexibility of job responsibilities, newly created professional activities (resulting from the collaboration), collective ownership of goals, and reflections on the process.

However, this institutionalized vision of collaboration may not be sufficient to tackle the problem of collaborative care delivery. In fact, as Paradis et al. [40] have shown in their study of 50 years on interprofessional collaboration in medical education, two important characteristics of collaboration are overlooked: First, the fact that collaboration is situated in a particular context and shaped by it; secondly, the context also influences "the ability to collaborate and to build relationships and common identities" (ibid, p. 870). Furthermore, depending on the country and the care situation, care integration practices can be more or less institutionalized; from interdisciplinary teams being at the center of the care plan and supported by federal agencies or care facilities, to situations in which they are less explicitly envisioned and just emerge spontaneously, as health professionals need to coordinate their work and communicate about patients. Using socio-technical systems theory, Pless et al. [43] have compared several multidisciplinary teams from four multiple sclerosis hospitals in Belgium, and identified important variation in care integration, along three dimensions: (1) whether multidisciplinary teams are limited to delivering care in a particular care phase or throughout the care process as a whole, (2) whether working relationships are maintained on an ad hoc basis or on a fixed basis, and (3) whether the therapeutic relationships are continuous or not, which reveals whether the care process is fragmented or integrated.

Presently, we are facing a transformation of work practices in healthcare towards collaboration that is multidisciplinary, ad hoc, and fragmented: A transition to fewer routines, with work groups that have little continuity. "Teamwork described typically in terms of content and rules (how things are done, habitually) must now be described in terms of process and accountability (why things are done, adaptively). Such team process has been described as teaming, negotiated knotworking, and collaborative intentionality, rapidly pulsating work that requires a variety of team players to come together temporarily for coordinated, cooperative, or collaborative activities, often in concert with other teams, in which situation awareness is best established through protocols such as briefing." [7:237].

In the following, we will focus on the concept of knotworking as an analytic lens through which to look at particular collaborative situations. These situations are of short duration, involving changing participants where control is distributed. Indeed, knotworking has been suggested by several other studies as a potential theoretical framework to address issues related to the development of the organization of work across boundaries, like interprofessional care teams [2,4,23].

#### 2.2. Knotworking

The concept of knotworking was introduced by Engeström et al. [24] to describe a cross-boundary way of organizing collective work that they argued was becoming more prevalent at the turn of the century and had a different way of organizing work than the prevalent 'command and control' model of hierarchical organizations. In this new way of working, there is plenty of coordination, but the number and changing institutions and people make it difficult to "... name a stable locus of control. The center does not hold"; "in each individual patient case, the combination of institutions, specialties, and practitioners involved in the delivery of care is different, and it is seldom possible to name a stable locus of control." [24].

In knotworking, collaboration occurs in episodes depending on the requirements of the particular, current situation. People involved in a knotworking process create and take part in improvised collaboration groups —called knots— in which otherwise loosely connected actors come together [42]. A knot does not fit the traditional definition of a team, which is typically understood to be a stable configuration, nor does it resemble the kind of pre-existing networks that workers might exploit. Knotworking represents an object-focused, situation directed, and highly distributed activity. Such collaborative work does not offer a central coordinator or locus of control, nor can it assume an "additive sum of the separate perspectives of individuals or institutions" [22:972]. Instead, in knotworking, "...the unstable knot itself needs to be made the focus of analysis." [22:972]. Thus, knotworking depicts a process in which temporary, ad-hoc collaborations - 'knots' - are formed, dissolved, and re-formed as the objective is constantly "reconfigured". A 'knot' - like knotworking - is an analytical concept that designates a temporary configuration of people (group) who engage in contingent collaborative processes. As an analytical concept, knotworking starts and ends when, from an emic perspective, participants think it does, or when from an etic perspective, this makes sense analytically. In other words, "knotworking represents dynamically changing and distributed collaborative work processes around objects and purposes that take their own life. These forms of collaboration happen and change over a shorter time, where boundaries are drawn for a time, rather than permanently" [8:535] Thus, knotworking is a specific kind of work requiring an extensive amount of 'articulation work' [46]. In stable work forms, some articulation work might be turned into routines (or be described in a procedure), reducing collaboration costs. In knotworking, this may be difficult because the specific event has not been encountered before or because the collaborative partners change from event to event. Even if one or more partners have encountered something similar before, there are others for whom this is new. Knotworking is contingent and temporary, which makes it difficult to be articulated through routines and procedures. As Strauss (1993) explains, the latter is a general aspect of any interactional aspect. He states, for example, that "Articulation stands for the coordination of lines of work. This is accomplished by means of the interactional process of working out and carrying through of work-related arrangements" (ibid, p87). Articulation work is a kind of 'type of work in any division of labor'. Strauss unfolds how actors seek to stabilize interactional processes and lessen the amount of articulation work by processes of working out arrangements in which agreements or procedures are agreed upon as to who does what, when by which means, etc. It is this 'working out' and subsequently resulting arrangements that are missing in the ad-hoc, contingent, and temporary collaborative events in focus in this paper, and which we label as knotworking.

In their work, Engeström and colleagues can be said to use the concept of knotworking in three different ways: As a general historical trend since the turn of the century in how collaboration is structured and plays out relating to changes in work and organizations [24]. As an analytical concept through which specific cases of collaboration can be analyzed, as in the case of a children's hospital where healthcare staff and parents work to create continuous patient care [24], or collaboration between librarians and researchers [25]. Finally, knotworking is perceived as a way to spur horizontal innovation - that is, bottom-up as opposed to management top-down – when different groups meet to solve problems between researchers and employees [25] quite similar to approaches within the field of participatory design. In this subsection, we will focus on the second use of the concept of knotworking.

Health researchers are characterizing the complexity of integrated care in which interprofessional collaboration at hospitals or in homes was necessary often found knotworking a useful concept in case analyses. In his study of a children's hospital aimed at initiating a collaborative effort to lower the burden of children and their families when navigating between different caregivers' organizations, Engeström analyzed how parents and practitioners (belonging to different caregiver organizations) collaborate to plan and monitor children's trajectories of care, and to share responsibility for the overall progress [23]. In the paper, he characterized knotworking as a "new kind of collaborative care in which no single party has a permanent dominating position and in which no party can evade taking responsibility over the entire care trajectory" (ibid, p151). Knotworking here involves both critical

episodes and the long-term trajectory of care. Similarly, Reeves & Lewin [45] conducted an ethnographic study of 49 health professionals in a hospital to understand interdisciplinary collaboration. They argue that knotworking is a better concept to describe the collaborative work than the concept of teamwork, and therefore that the forms of teamwork promoted in health care policies do not adequately depict the actual work going on. Lingard et al. [35] have used knotworking to examine the complexity of managing a patient with different clinical expertise facing emergent challenges. In their study of a transplantation service, they described knotworking as a "fluid, horizontal web of symbiotic transactions and translations in the transplantation team that are neither readily bounded not entirely elusive. This web can be traced, but it will not hold still; it is vulnerable but difficult to eradicate; its center cannot be precisely pinpointed, but it exerts agency" (Ibid, p. 874). For these authors, the division of labor and objectives shape knotworking. As the previous authors, Lingard et al. contrast their findings with the medical education literature about collaboration in which roles are stable and boundaries of authorities are clear: In knotworking situations, roles are fluid and subject to the influences of particular situations and boundaries are blurred. The utility of knotworking to move beyond an understanding of teamwork and to contrast with usual definitions of roles and authorities can also be found in the study by Colvin (2017) of rapid response teams in a large intermountain hospital [17].

Hurlock-Chorostecki et al. [29] proposed in their study of 24 nurses employed at six hospitals in the UK to distinguish between "rapid" and "brief" knotworking: Rapid knotworking refers to very short (1 minute) interactions for rapid negotiation, improvisation or delegation, while brief knotworking lasts longer and consists in information sharing and inquiry that often result in shared decision making. Rapid knotworking, though necessary in life-threatening situations, may, in the long term, hinder interprofessional care; only the nurses who are the initiators of the rapid knotworking retain "the essence of the knot" for further related knots, while the other collaborators do not have this knowledge. This difference between rapid and brief knotworking was also identified in one of the rare studies illustrating knotworking in home care settings [2].

Most of the above mentioned studies use knotworking for the analysis of teams and interprofessional collaboration healthcare, but do not include technology nor innovation in their studies. Indeed, to our knowledge, studies about designing information technologies to support this kind of cooperative work are lacking. Despite the concept's origin in Engeström and colleagues' projects in and theorizing of innovation, learning, and designing new artifacts, this line of research has not been pursued to any significant extend (See though Bødker et al. [9]). We wish to take up that line of research again, and based on the comparison of our two cases, we will return to the relations between knotworking and design in Section 5.

#### 2.3. Computer-support for ad-hoc collaboration in health care

CSCW and medical informatics researchers have widely addressed the issue of how to design supporting technologies for ad hoc collaboration in healthcare. In this paper, we focus on non-clinical settings where numerous studies have been conducted to describe and analyze the care practices of home care clinicians, in the framework of local healthcare networks, or integrating the informal caregivers and the patients in the case of chronic care [6,11,47]. Their results have led to identifying the main requirements for designing computer-based systems to support these home care networks. In particular, care actors need support for scheduling visits, disseminating information, retrieving information from others, coordinating treatments, and creating care plans [41]. What is common across these requirements is the fact that the existing shared home care records (whether paper-based or electronic) only partially address them. To fill this gap, several principles have been identified to improve home care records; systems supporting collaboration in these settings should offer the following items:

1. Activity awareness, or rationale in context: Care actors need a core narrative more than information filed in bureaucratic forms [21,41].

- 2. Fluid collaboration, by supporting ad hoc collaboration rather than formalized administrative procedures. Healthcare professionals should be able to contact other professionals helped by the care plan if they feel it is needed [21,27].
- 3. Support for collective decision-making process among professionals, and not just for sharing accomplished decisions. To do so, communication features should be integrated with the home care record [41].
- 4. Different sources of data (automatically collected through sensors, collected by professionals, or by the patients and relatives) should be considered, and it should be possible to integrate rich data from, for example, video and audio [3].

As previously mentioned, we aim at contributing to this research area by presenting two cases in two European countries. As stated, we mobilize the concept of knotworking to analyze these work arrangements that become increasingly temporary and shifting. Further, through a comparison of the two proposed design solutions, we outline design guidelines for this kind of shifting and unstable cooperative work. The cases are from two European welfare states, with universal healthcare, which of course have cultural and regulatory differences. However, when conducting our analysis, we focused on the collaborative practices and the way IT solutions have been designed to support them without looking at the cultural or regulation differences. In fact, regulations of healthcare did not emerge as an issue in the analysis of their collaborative work.

## 3. CASE 1: THE CAREFACILITY IN DENMARK

The CareFacility is a municipality-run rehabilitation care facility. Admission, stay, and discharge from the CareFacility often involve a wide range of coordination activities, each with its own set of diverse external collaborators, including general practitioners, relatives, and hospitals. At the CareFacility, an ethnographic study and a set of co-design activities were conducted to identify operational challenges and design possibilities. The study developed the idea of collaborative infrastructures for flexible use, meaning that people and organizations can collaborate around issues, even if some partners do not know about each other and do not share a common collaborative system. The study will now briefly be explained in order to inform our discussion of knotworking (for a full and detailed presentation of the case, including a more extensive methodology description, please see [12]).

## 3.1. Context

Not all patients can immediately return home as they are discharged from a hospital. Their medical treatment may be completed, but due to their former illness or consequences thereof, they may have to learn new skills, handle new assistive technologies, etc., before they are able to again live independently or semi-independently at home. The CareFacility is situated between the hospital and private homes to support these patients by providing them with the possibility to stay a few weeks to rehabilitate further and to learn how to handle, for example, everyday chores with a newly amputated arm, or to rebuild body-strength after a longer stay at the hospital. At the CareFacility, each person has her own room, and there are a few common spaces and additional training and rehabilitation facilities. However, training may also occur in a person's room or other spaces like the shared dining room, if these are more suitable than the gym. Care staff is available 24/7 to handle any medical or other needs that may occur. The care staff also handles much coordination with the hospital, each person's general practitioner (GP), the municipality, taxi companies, pharmacies, and relatives. A lack of tools to support the needed collaboration between different people and organizations challenge care on a daily basis.

## 3.2. Methods

The study was a collaboration between the municipality, the CareFacility, a university, and a private company interested in healthcare logistics and information systems. The study lasted for five months and was conducted as a combined ethnographic study and a set of co-design activities. All participants

(i.e. CareFacility staff members and care receivers) volunteered to participate having been informed about the project and its overall scope. All signed an informed consent-form. The care staff and the municipality participated as part of their ordinary workhours, while the care receivers participated without pay and in their free time. No ethical board approval was required.

Through interviews, observations and shadowing, video observations, diaries compiled by eight staff members, and five co-design workshops, the project partners and the care staff members identified and learned about particular operational challenges present at the CareFacility. Interviews and observations were mainly conducted to create an understanding of the physical space, activities carried out, and how staff and patients experience the CareFacility, and where different activities were carried out. Furthermore, five co-design workshops were conducted and included care staff, a university researcher, and a representative from the private company. In two of the workshops, daily leaders of the care facility also participated. The first workshops followed after the initial interviews and observations and focused on verifying findings from the early ethnographic work and on creating a shared understanding of what collaborative tasks are carried out at the care facility and the people involved. Based on this initial work, a diary was developed. Eight staff members returned their compiled diary after about two weeks. At this point, the project partners had created and shared a rather detailed understanding of the type of external collaborations that took place and concluded that there was no single, uniform way to work with the external partners. One full day of video recordings of the care workers' office supported the findings and verified that much time was spent on collaborative work with external partners, such as trying to get hold of people over the telephone. Based on the findings and the project's focus on supporting collaborative work with external stakeholders, the final two workshops investigated design opportunities and how to improve external collaborative work, including investigating design strategies for collaborative support where the collaborator may not be known on beforehand. A summary of methods is provided below in Table 1.

Table 1.	Overview	of method	is in the	CareFacilit	y project	

Data generation	Data analysis	Conceptualization	
Field studies, interviews, workshops, diaries, video recording by Author 3.	Grounded analysis by Author 3; co-analysis workshops with care staff and Author 3; co- analysis by CareFacility management and Author 3.	Author 3 and Author 2.	
Project participants: CareFacility care staff; CareFacility management, municipality, a private healthcare IT company, Author 2, Author 3.			

## 3.3. Collaboration at the CareFacility

During the study, we learned that the CareFacility collaborates with, and depends on, many external stakeholders. Each patient's trajectory is different and requires its own set of actions to ensure a positive health outcome. Plans and templates have been developed to support staff and patients and their activities, but in reality, such templates can rarely be followed 'as is'. More often, needs emerge either from the patient's or care workers' side that cannot be handled locally at the CareFacility: Plans must be rescheduled (e.g., a hospital visit), someone must get extra medicine during a weekend, the municipality may lack some homecare workers to receive a discharged patient at home, or a relative must be contacted to assist in a task. Many of these activities require sporadic and hard to foresee collaboration with actors outside of the CareFacility. The first half of our project led us to understand that among the identified activities that require collaboration at the CareFacility, there are a set of activities that takes place more often compared with other activities. Likewise, some of the external actors are more

frequently involved in these collaborative activities compared with others. Figure 1 summarizes these findings from the early ethnographic and co-design work showing that a set of relatively frequent core activities exists and that there is also a set of core actors with whom the CareFacility often collaborates. Still, less frequent activities and actors are also exemplified in the figure. A recurring partner may be a specific hospital department, while a less frequent may be the police. The CareFacility often works with the patients' relatives, but these relatives are different for each patient. So, while they frequently collaborate with the role of 'relatives', they always encounter new people in that role.

To support a positive care trajectory, different actors must hence collaborate, even if a (well)established relation does not exist beforehand. These types of collaboration are created as a result of one or more actors' emergent needs where people collaborate for a brief time period (the length of a few telephone calls or up to a few days) to handle a specific issue. Most needs originate from the activities at the CareFacility, but not all. It may be a hospital that contacts the CareFacility, the municipality, or maybe a relative. What characterizes these situations is that they are important to resolve, they are often difficult to plan or even to foresee, they involve more than two partners, and they are not presently supported in the different organizations or with technology.

Extended Care Activities			Contact with case officer Contact with pension office	
Core Care Activities Discharge planning Contact with referral office Contact with external there Booking and coordination transportation Contact with resident after discharge	apists Contact with local care c Contact with home healt Post-discharge communi	nt ation with relatives list l tion with resident senter hcare workers cation with relatives relation to discharge	Contact with pension office Emergency admission to hospital Contact with state administration Contact with coordination teams at hospitals Personal aid support (ordering, repair etc.) Transportation to diverse treatments Contacting the police, if a resident disappear Contacting a coroner in case of death Locate a persons private newspapers Pharmacy General practitioner Booking visits to a hair dresser Request pickup of personal aids Treatment follow-ups Contacting relatives	
Extended Care Network			Dunia de una se se se dia sé se	
		House support tea	0	
Core Care Network	Therapist at Care Facility	Care personnel Taxi	Ambulatory team Neuro-team	
The resident Next of kin Referral center Local care center Hospital General Practitioner (GP) Home helpers	Pharmacy Reception/Receptionist GP Secretary Cleaning staff Nurse Doctor at hospital Therapists at Local care center	Home training tear Falck Hospital transport Home helpers tear Mobile rehabilitati Bus company Local care center a Home helper nurs	Retirement support worker team Neighbor m leader Friends ion team Referral to special houses Health clinic admin. Assistive tools depot	

Fig. 1. Examples of core care activities and collaborative partners. From [12].

The different partners are not part of the same organization (i.e., they do not all work at the CareFacility) and their main work tasks are not to collaborate with the CareFacility. Each partner rather provides work for their own organization, and therefore their work rhythms are not necessarily aligned with that of the CareFacility. To get hold of and to speak with the right person on the telephone can, for example, be a problem, as the different organizations offer different telephone times, etc. To get hold of the right GP and get the right medicine schedule sent over to the CareFacility for a particular patient may be a 15 minutes' task, but often spans over several days as the right people must be tracked down and contact established, the GP must compile and send the schedule, etc. The current collaboration is, therefore, rather asynchronous by nature, but there is currently no support for this asynchronous way of working. Furthermore, there is no shared overview that may strengthen the collaboration by contextualizing the different actors' needs, availability, and resources.

#### 3.4. Design solution

As described above, the challenges of collaboration around the CareFacility and its patients come from its position in-between other organizations and actors on whom it depends. To support collaboration in a context such as the CareFacility, where multiple stakeholders across organizations must collaborate, sometimes without prior knowledge of each other, the final two workshops and the analysis of the project results led us to identify a set of important characteristics. As the CareFacility staff have little or non-control of the work in other, external organizations, a collaborative tool should stabilize the brittle work arrangements. Also, to increase the transparency and needs among the collaborative actors, it is useful to make the different collaborators' fields of work more transparent to the other stakeholders. Further, a supportive tool should provide a comprehensive, rather than a partial overview of the involved collaborators and support both ad hoc collaborations and articulation work. This is important, for example, when supporting planning and onboarding of new stakeholders in contexts where not all collaborators are known beforehand. Again, this work is described in more detail in [12].

In response to the identified collaborative challenges and needs, the project developed a timelinebased design. The design substitutes the current whiteboard providing a patient overview located in the staffs' office that, however, only supports a smaller part of the existing collaborative needs. The whiteboard analogy supports the staff members to appropriate the new tool easier as it is similar to the analog whiteboard they use today. The current whiteboard focuses mainly on what happens 'now' and does not provide an effective way to plan ahead or to look back on what happened, for example, two weeks ago. An overview accessible for all staff members is missing in the current solution; there is no calendar-type functionality. The current overview also only supports local work as the traditional whiteboard cannot be accessed remotely. The new timeline-based design is built around a large touchbased screen (see Figure 2). The interface is divided into four main parts; (Left) The current list of patients, (Middle) The actual timeline of a patient and its elements, (Top) Collaborative tools plug-ins, and (Bottom) Activities that can be inserted into the timeline as elements. Additionally, there is a headline that allows the user to see which (i.e., what patient's) timeline has been selected, a free text search-field and a Home-button.

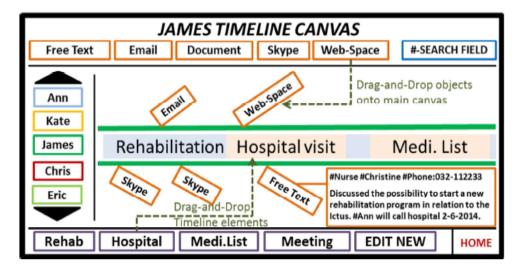


Fig. 2. Big screen with touch functionality running the CareFacility's collaborative tool. From[12].

Each patient starts with an empty timeline in the middle of the large screen. The staff can put different activities on the timeline, like visits to the hospital, rehabilitation, to verify a medication list

from a patient's GP or meetings with relatives. These different activities will require different forms of coordination and sub-activities. A hospital visit may, for example, require the booking of a taxi, and a meeting may require a discussion about suitable times and dates where all participants can meet up. Depending on the actions needed to coordinate an activity, different collaborative tools may be used. If the staff needs to verify a medication list, for example, they may first try to call the GP by phone. They can add a free text field (from the top list) to the medication list activity on the timeline. In that field, they can write when they called, the telephone number, and finally with whom they have spoken and what they agreed upon. In this way, other staff members can follow what has happened and can potentially assist. The GP can receive a link to a private and dedicated view of the activity via email. This also appears on the timeline as an email-resource. If the GP opens the link on his or her own device like a computer in the physician's office, a webspace resource will be added to the timeline, and the doctor will remotely, from his or her own device, be able to verify the medication list when time permits. The private view allows the GP to see some elements on the timeline, and then to understand how the verification of the medication list affects other activities at the CareFacility or even other partners that may be involved in the process. The integration of different communication tools from the top part of the screen provides both resources to collaborate and documentation of past (and planned) events. From the above description, it should be clear that the overall control and initiation of timeline events and collaborations are in the hands of the CareFacility; they are the ones to invite other actors to take part in collaborations.

## 4. CASE 2: HOMECAREALLIANCE IN FRANCE

The HomeCareAlliance is a local association in a middle-sized city of France that gathers health professionals and professional caregivers with private practice. The members of HomeCareAlliance work together with the explicit aim to preserve the quality of life of patients at home. We conducted a three-year design case study to identify the challenges the members of this association face when collaborating. We will report briefly on the study and its results below. A more detailed description of the study including a more extensive methodology description can be found in [2].

## 4.1. Context

In France, most home care actors have an independent, private practice; a GP prescribes a nurse's intervention, without knowing which nurse will do the work and how the work will be carried out [9]. Home care actors organize their work loosely, optimizing their time [13]. If a problem occurs, either the patient or the nurse contacts the GP. However, for some patients with complex situations who desire to stay at home, care actors must coordinate their effort in close cooperation to allow for home care and avoid unnecessary hospitalization of the patient.

In this context, the HomeCareAlliance promotes a collaborative approach to providing home care. In the words of its co-founder (a GP): "We want to create a care team that works for actors with private practice. We want to create collaboration out of the walls". The HomeCareAlliance then consists of a wide range of care and health professionals with private practice (general practitioners, nurses, physiotherapists, pharmacists, professional caregivers, etc.). Depending on the patient's situation, the care actors vary, and in some cases, family caregivers and the patient are active members of the care plan. When they start taking care of a new patient, members of the HomeCareAlliance organize what they call a "care meeting" at the patient's home. This meeting allows different care actors to define a dedicated care plan. This is also the occasion to introduce a paper-based notebook called "liaison notebook" in the patient's home. The notebook enables all care actors to exchange messages and to adapt their practices regarding the evolution of the patient's situation. Using a paper-based notebook or a care binder is common in homecare practices, but each profession usually has its notebook (one for the professional helpers, another one for the nurses, etc.). Thus, a small number of actors were aware of the HomeCareAlliance notebook. Besides, it is difficult for new care actors to understand how or why they should use the "liaison notebook". Therefore, the founders of HomeCareAlliance contacted our ACM CSCW 2021 Submission

university to discuss if a digital version of the liaison notebook could be developed to ensure a proper asynchronous discussion among all the care actors.

# 4.2. Methods

We used ethnographic methods during the three years of our design case study [44], combining interviews, observations, and discussion sessions. No ethical board approval was required for the whole study. Interviews and discussion sessions took place in a meeting room of the University, always out of office hours (in the evening or during the week-end), as asked by the practitioners. All of them signed an informed consent. The observations were conducted while shadowing a registered nurse (one of the two founders of the HomeCareAlliance) for three days. Patients were informed of our presence by the nurse who collected their consent for our visit orally. We conducted two design workshops with six participants members of HomeCareAlliance (three home helpers, a registered nurse, a physiotherapist, and a general practitioner).

In the first workshop, we used scenarios and mock-ups to illustrate our interaction design options and assess the design implications that emerged from our findings. Participants had printed copies of the mock-ups, and they commented on our propositions and suggested new ideas. All the suggestions were arranged on a board and guided the design of the prototype. At the second workshop, we presented a prototype of the application using scenarios. Participants worked with the prototype installed on PC tablets and gave us feedback that guided our first version of the application. The application is accessible via a tablet PC that stays at the patient's home. The care actor has to have physical access to the tablet to use the application. The patients or their family usually grant physical access.

In contrast to the CareFacility, the patients and their families are in overall control of the tool. We conducted a five-month pilot study, where five patients and their care network used the tablet while staying at home. All the participants (patients and care network, including professionals and relatives) provided informed consent, indicating their agreement to participate in the pilot study. During the pilot study, we regularly visited the patients and gathered information about the application's use when care actors (familial or professionals) were present. Finally, we had a discussion session to evaluate the pilot study with four of the care actors involved in the study (two home helpers, a registered nurse, and a general practitioner).

Data generation	Data analysis	Conceptualization	
Interviews, shadowing,	Grounded analysis - coding rounds	Author 1 and Author	
observation of the association's	by Author 1 and resulted codes	4.	
monthly meeting, discussion	discussed with Author 4; co-analysis		
sessions, design workshops, liaison	of liaison notebooks by Author 1		
notebooks, and video recording by	after discussions with the founders of		
Author 1.	HomeCareAlliance.		
Project participants: HomeCareAlliance members (healthcare practitioners and home helpers),			
patients, informal caregivers, Author 1, Author 4.			

## Table 2. Overview of methods in the HomeCareAlliance

## 4.3. Collaboration in the HomeCareAlliance

We observed that the work of care actors around a patient has a rhythmic pattern depending on the patient situation. The care actors can be involved in an intense collaboration (when a matter of concern emerges) or less intense if the patient's situation is stable, and the current care plan suits the patient's needs.

When issues emerge, the current care actors meet and invite all the new care actors that are needed (according to the issue that arises, it may be a dermatologist, a psychologist, a neurologist...) in order to adapt their practices to face the issues. According to the emergency level, this kind of discussion can take place asynchronously, mediated by the paper-based liaison notebook, or synchronously, face-to-face or via phone calls. When the care actors consider the issue as challenging for the current care plan, they organize 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 aims to understand the problem, discuss options, and find compromises to reconfigure the care plan. Once the members resolve an issue, the "crisis" is over, the situation is stabilized, and so, 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. The care actors might also work simultaneously to address different issues that arise in parallel. This cycle repeats itself according to the evolution of the care condition of the patient.

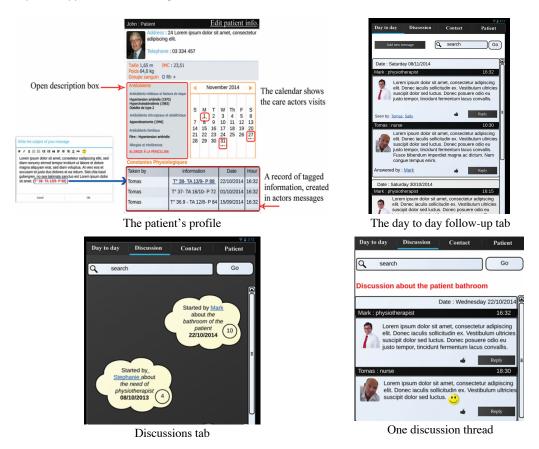
Though underspecified, the liaison notebook offers a place for the care actors to discuss their care activities and thus, highlighting problematic issues, which trigger the collaborative episode. This notebook informs care actors about the evolution of a patient and offers a place to discuss the care plans' adaptation. However, the notebook is ignored or not used a lot by the new care actors as we mentioned before. Despite the post-it on the notebook that invites all care actors to leave messages, for new care actors the "liaison notebook" does not belong to them (in particular when they are employees of an organization that already offers a notebook to keep track of all the actions). Besides, in case of the absence of issues, the care actors do not meet, and thus they do not communicate or share knowledge about this collaborative way of taking care of a patient.

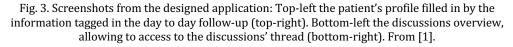
HomeCareAlliance patients can count on the collaboration of the care actors when a problem occurs. However, even if the HomeCareAlliance would like to include more health professionals from outside the association, they have difficulties in establishing collaboration. Indeed, integrated care and collaboration in the context of home care represents a shift of practices in France [15]. The founders of the association contacted us (the university) to help them find a way to make their collaborative practices more sustainable, and to convince more professionals to join and work in this collaborative way.

#### 4.4. Design solution

The paper-based notebook's actual use is not sufficient in a context where new care actors might join the care group, as mentioned. The liaison notebook's role from the HomeCareAlliance goes beyond documenting individual care actors' work and aims to enable communication and discussion among care actors. However, this feature is not easily detectable for new care actors.

To enable the collaboration to move beyond the liaison notebook's limits, we proposed a new application that we designed with and for the HomeCareAlliance. It offers a place where care actors can exchange messages by creating a new message, comment on the other messages, and acknowledge that they have read a message (Figure 3, bottom right). Each care actor can create a profile to access the application, where they put information about themselves, including a photo (taken with the tablet) associated with all their messages. Another way to participate is to indicate a name and a profession to access the application, read messages, and leave a message.





The application provides a patient profile where care actors document the information necessary to support medical, social, and logistic aspects of home care (Figure 3, top left). One can trace the essential events that affected or might affect the current care plan by looking at it. These events are ordered chronologically, which offers a vision of the patient trajectory. All the messages written in the day-to-day tab (Figure 3, top right) and belonging to the same thread are accessible from the discussion tab; this feature allows care members to track discussions about issues that emerge (Figure 3, bottom). The application also provides a list of the current care actors around a patient, together with their contact information. When clicking on the profile's picture of a care actor, one can get details about this person's activity on the application, for instance, the list of messages recently posted by her and the history of her visits. For a more detailed description of the application, see [1].

During the pilot study, various care actors used the application, including family members, homehelpers, professional caregivers, health professionals, and social workers. For each of the five patients, their GP created a profile. Many care actors created their profiles and started using the application without our help. The different actors exchanged messages about the patient's situation, their daily tasks, asked questions, and addressed issues beyond the medical condition of the patient. For example, a family member and the home-helper exchanged messages about a problem with water leaking in through the house's exterior door.

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## 5. KNOTWORKING – A USEFUL ANALYTICAL CONCEPT FOR COLLABORATIVE PRACTICES IN HEALTHCARE

In both cases of the CareFacility and the HomeCareAlliance, collaboration is, as we have outlined above, ad hoc, temporary, and shifting with regards to collaborators, aims, and processes. We find that collaboration in both cases can aptly be conceptualized as knotworking, as defined by Engeström and colleagues: "[...] dynamically changing and distributed collaborative work processes around objects and purposes that take their own life. These forms of collaboration happen and change over a shorter time, where boundaries are drawn for a time, rather than permanently" [8:535]. Thus, knotworking represents a way of re-organizing the work collectively that emerges in a cooperative ensemble which participants work relatively loosely around an evolving object. Hence, cooperation happens between semi-autonomous entities (organizations or persons) which may not be used to cooperate, yet, in certain cases their cooperation might be the only way to overcome critical situation. What characterizes knotworking is the high reactivity and reconfiguration of work arrangements. These kinds of collaboration in home care will most likely increase as hospitals strive to reduce number and length of admissions, and authorities strive to enable citizens in need of care to stay at home rather than being at a nursing facility.

For instance, one of the patients from the HomeCareAlliance that we observed was Paul. He was 80 years old and was treated at home with his wife being his main informal caregiver. Paul suffered from an inflammatory rheumatic disease that evolved in spurts, and the pain justified a cortisone-based treatment. A home-helper was visiting twice a week to help his wife in caring activities. A registered nurse and the general practitioner were also visiting Paul when needed (for instance when an injection of cortisone was needed). As Paul started to go through severe diabetes episodes caused by the cortisone treatment, a care meeting took place where care actors (including Paul's 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 document them. This *knotworking* allowed all the care actors to adapt their practices, including the documentation practice as the patient needed to keep a record of blood glucose. Six months after this episode, Paul was admitted to a hospital after he has been diagnosed with a prostate cancer. Once Paul returned home, all regular care actors along with the specialist worked together (another knotworking activity) so that caring at home was still possible and safe.

The admittance or discharge of a care receiver at CareFacility are events that are common and in that sense routine, but which nonetheless often generate a number of knotworking activities, since the care receivers, relatives and municipality social workers often have to cooperate and find solutions to challenges and problems specific to each person and life situation: A home has to be fitted with supportive tools or be partly rebuilt to better support the person being discharged from the CareFacility, for example. Such remodeling may not only require coordination and collaboration between the care receiver and the relatives, but often extends to involve also municipality workers, external contractors and landlords.

As we can see in these examples in our two cases, such collaboration involves considerable communicative and coordinative challenges, which raises the question as to how those can be met. We have already suggested two different design solutions developed through co-design practices much alike the third meaning of knotworking as an innovation method (See section 2.2), but we will not further discuss that aspect, since our focus in this paper is to develop general design guidelines: We find the concept of knotworking to be an apt conceptualization of collaboration in home care, but as indicated in the Related work section, there has been little elaboration on the concept regarding design beyond Engeström and colleagues' work. To move in the direction of design, the following sections will proceed in the following way: First, we will reflect and build upon Engeström and colleagues' work in the light of our two cases, and, second, elaborate on the knotworking concept to inform the design of technology.

#### 5.1. Complex knotworking

Engeström developed the concept of knotworking twenty years ago, in the context of organizational and technological innovation projects in organizations such as hospitals and libraries. When comparing our two cases to that original work, some nuances stand out that suggest that in our cases, we are facing a more complex kind of knotworking that we hereafter are calling "complex knotworking".

As previously mentioned, the knotworking concept emerged out of Engeström and colleagues' collaboration with a children's' hospital, where gaps and discoordination of care for children were recurring challenges. Through workshops with healthcare staff, parents, and researchers, a fourfold solution was proposed: The appointment of a coordinator, the draft of a written care agreement as to which actor was responsible for what; confirmation of the care agreement through negotiation with all involved actors (including the parents); and, finally, automatic feedback in the form of a copy of the patient's (i.e., child's) care record to all stakeholders of the care agreement after each visit [24]. We will not go further into detail with the case here, but we note that the solution consists of the following ingredients: creating a fixed work role to whom overall responsibility for the care trajectory is assigned (the coordinator); an agreed-upon division of work; and automatic update of information to all the stakeholders. Also notable is that the knotworking challenges could be resolved with a stable, long-term solution. To a large extent, this is probably contingent on the involvement only of one, stable organization, one coordinative device (the patient record), and a limited number of (known) collaborators.

In contrast, our cases are characterized by knotworking across multiple organizations, with multiple, but not shared coordinative devices, and a varying and unknown number of collaborators. This, in turn, has implications for what kind of solutions will work. Creating, for example, a coordinator as a dedicated work role is possible at the CareFacility, but not in the HomeCareAlliance. Still, the person appointed for such a role may have specific authority in the actual CareFacility organization, but seldom in other external organizations with whom the CareFacility may collaborate. A care agreement specifying a division of work beyond already existing professional boundaries and responsibilities between home care workers, GPs, etc., is not possible since the kind of knotworking situations constantly change: A new prescription is required; a broken arm must be treated; a scheduled transport has to be changed. Automatic updating information for all the stakeholders is not possible, because of the variety of changing collaborators (taxi schedule and driver; medication prescription, etc.) and different communication systems (hospital EHR, GP EHR, taxi booking system, etc.). Thus, the design solutions need to be - and are in our two cases - open to knotworking instances that are cross-organizational, open-ended regarding possible collaborators, and should enable information sharing in this context. While knotworking in the cases of Engeström is also across boundaries, in our cases, they could be said to be (more) complex, as different knotworking situations constantly emerge, that cannot easily be fixed.

Comparing our two cases, we identify three characteristics of collaboration in knotworking that are particularly challenging when designing technology support: 1) collaboration happens between a dynamic number of actors (who are usually loosely connected), 2) the collaboration happens in episodes, and, 3) cooperative work arrangements are constantly negotiated.

#### 5.2. A knot involves a dynamic number of actors

Knots emerge as a strategy to handle collaborative challenges that require work by different actors. These actors, who are loosely connected, come together in a knot either spontaneously or as a response to a request, for example, from a person or organization. Depending on the reason to create a knot and who participates in it (organizations, individuals, etc.), the knots are shaped differently.

In Case 1, the CareFacility can, for example, initiate a knot to prepare the patient to return back home safely. Here, the CareFacility takes the role of the initiator and the coordinator of the knot. As an organization, it can influence or enforce a way of doing the work, or the type of activities to negotiate or achieve (see Figure 2). At other times, for example, in the admission of a new patient, the knot is

initialized by the hospital or the municipality, and in this case, the CareFacility just participates as one of the actors in the knot. In the first example, where a patient returns back home, a number of different actors may or may not be involved. The CareFacility and the actual patient are naturally involved in this task, but other actors may also become involved at different levels depending on the situation at hand. Often, a relative or a close friend is involved in both the planning and preparation for the patient to return home and the actual transportation. However, transportation may also happen by taxi, and a municipality case worker may be involved in the discharge-process. To complicate the matter, the role of, for example, a relative, will be assumed by different people depending on who the patient is.

In Case 2, most of the actors of the HomeCareAlliance participating in a knot are health professionals with a private practice (e.g., general practitioners, specialist doctors, nurses, etc.). These actors have regulations that govern their practices, and they work in the home of the patient. They might take care of the same patient, but as independent professionals, they do not belong to any organization that coordinates and plans their possible collaborative work "around" a patient. They do not belong to any predefined (multidisciplinary) team. However, when a patient's situation requires the collaboration of several care actors, they adjust their work. For example, when a patient gets discharged from the hospital and needs a follow-up care-plan at home, a nurse or the patient's GP can initiate a knot, inviting the other necessary actors to take care of the patient collaboratively. Thus, in the case of HomeCareAlliance, the participation of care actors depends on both the condition of the patient as well as the willingness of the care actors to communicate and coordinate their work. New care actors might join the care group at any moment of the patient's trajectory and thus become part of the knotworking process. While some care actors might be relatively stable in the care group like the GP or the nurse, other actors might have a high turnover, like home-helpers, for instance.

In both cases, collaboration occurs between a relatively dynamic number of actors. In the case of the CareFacility, each patient's admission, stay, or discharge can create different occasions to redefine the actors needed to support the patient. The CareFacility often plays the role of coordinator that opens up the collaboration to integrate participants from outside the facility. In the case of the HomeCareAlliance, each patient is treated by an evolving group of care actors. Depending on the patient's condition, the care actors around the patient vary, and might belong or not to the HomeCareAlliance. No single care actor plays the role of gatekeeper of collaboration permanently: Every care actor can signal a problem and invite others to collaborate.

#### 5.3. Collaboration in and around a knot occurs in episodes

Looking at our two cases, we have identified that collaboration in and around the formation of a knot has an episodic rhythm and can be divided into two types of knots: Predictable and unpredictable. What we call a predictable knot depends on events that can be foreseen or reoccur and can somehow be planned (e.g., a patient arrives at the CareFacility) and where the actors may somehow be identifiable beforehand (if not the actual person, then the role, e.g., transport). An unpredictable knot is the result of an unforeseen event, like a problem that emerges or if a patient has needs that are different from previous experiences. For instance, a rather healthy patient may suddenly fall, and as a result, the needs in terms of care and support at home may change. The unpredictable knots are characterized by unique and individual needs and hence are challenging to plan and prepare.

With the CareFacility, activities often require interaction or collaboration with external actors. It can be to make a phone call or to retrieve some data from some external actor. While these interactions are often predictable and brief, the work may halt until the right data and interactions have taken place. The more unpredictable episodes can occur when, for example, an unforeseen problem emerges and hence requires specific and tailored collaborations and solutions. With the HomeCareAlliance, on the contrary, most of the knots are unpredictable; the collaboration happens due to events that care actors cannot manage in the traditional individual ways of care (i.e., a doctor prescribing medication and care acts, and other care actors who have to intervene to provide care according to the prescription). The initiators of a knot have to identify the care actors required to form a knot for a particular situation.

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After the formation of a first knot, there may be some episodes that can be anticipated as when, for example, a patient has a planned surgical intervention or chemotherapy: Here, the actors can anticipate a knot for preparing the care after the medical event. To sum-up, whereas at the CareFacility, much can happen, but the admitted patient will follow a trajectory with some known activities (at minimum admittance, stay and discharge), in the HomeCareAlliance, most episodes cannot be envisioned, or they cannot be easily identified before they emerge.

## 5.4. Work arrangements in a knot are constantly negotiated

As we mentioned earlier, a knot may form when an event that requires the collaboration of mainly loosely connected actors occurs. As the members of a knot do not normally work together, they must start by adopting and negotiating the cooperative work arrangements. For some knots, actors have to start from scratch, while in others, there are some predictable or agreed upon activities in which case there is less to negotiate.

At the CareFacility, actors actively initiate a knot or respond to an invitation to join a knot. To some degree, the CareFacility as an organization can have some control of the formation of many knots, but can, at times, experience difficulties to get external partners to feel that they are part of a knot. With the HomeCareAlliance, most of the knots spontaneously emerge as actors are facing a problem. Even when there is an initiator of a knot who invites the other actors, there is less or no preconception of the work activities or their arrangements. The actors who participate in knots around the same type of patient might share best practices, but they cannot enforce their way of working. It is less prominent who is in the knot or how the involved actors achieve the knot's objective compared with the first case. As the CareFacility is an organization that 'owns' many of the processes, they can integrate into their work practices some cooperative work arrangements that might be opened for future knots. The application designed for the CareFacility suggests one way to support this computationally. In this case, the cooperative work arrangement is partially shaped by the experience and the routines of the organization. With the HomeCareAlliance, members of a knot are individual professionals who do mobilize their professional network but do not formalize cooperative work arrangements. Thus, whenever they come together to form a knot, they have to negotiate the cooperative work arrangements. For example, a patient who begins to suffer from diabetes after a cortisone treatment has new care requirements that entail a different coordination process: the nurse has to increase the number of home visits and to keep a log of the patient's glucose levels to inform the doctor, who will then know if the treatment has to be adapted and how. Looking at our two cases, we can say that knots involve different levels of negotiation depending on the stability of the activities handled by the knot, as well as the type of participants (individuals, or organization). In both cases, the knots often involve actors that do not share a common or aligned work rhythm. As a result, work arrangements and knot participation are commonly negotiated and renegotiated during a knot's lifespan.

Summarizing the above subsections, we can say that complex knotworking involves a dynamic number of collaborators, a multiplicity of different knots, episodic instances of predictable and unpredictable knotworking, and constant negotiation of how to cooperate and communicate to solve the challenge at hand. We argue that these characteristics of complex knotworking must be considered when designing supporting information technology and we base the development of our design guidelines on those three characteristics in the following comparison of the two design solutions.

## 6. HOW TO COMPUTER SUPPORT KNOTWORKING?

Because of the inherent characteristics of knotworking, there is presently no established organizational or computational support to support knotworking for the CareFacility or the HomeCareAlliance. In the following, we will discuss the two design solutions that, independent of each other, were proposed in each respective case in order to deliberate on how knotworking in general could be supported. This

discussion leads us to identify general guidelines to design information technology to support knotworking.

## 6.1. A dynamic number of known and unknown actors

One difficulty with knotworking is that we cannot know in advance who will need to access the supportive computer system and with which kind or level of access (for instance, a taxi driver is not supposed to access the same kind of information as a nurse). Access to information has to be possible and restricted at the same time. The two cases display different solutions: The large whiteboard located is central to the solution at the CareFacility, and here access is largely based on physical proximity, though the system or parts thereof may also be accessed by other actors outside the CareFacility via the Internet. So, information is also available to anyone with access to the Internet and the required login and corresponding role-based access rights. The solution in the HomeCareAlliance case is based on a portable and hence mobile tablet that primarily can be found in the patient's home but can also be carried around, for example, brought along to consultations at the general practitioner's office, to the hospital, etc. Access to information is then not related to the Internet but is made possible when one has physical access to the tablet. Hence, there are obvious differences between the two designs, such as the solution being primarily 'owned' by the CareFacility in Case 1 and by the patient in Case 2. Consequently, the security in Case 1 is mainly based on login-based access- and role-control managed by the CareFacility, whereas in Case 2, security is mainly based on physical proximity and access to the device. While we do not make claims on whether our discussed system designs implement state-of-the-art security mechanisms, they have explored different ways of accessing, granting, and restricting data access in knotworking situations. Based on the above observations, our first generic design guideline is to:

#### Define flexible access to information (possible and restricted at the same time).

Since the number of actors is dynamic, and their role or identity often is unknown beforehand, the overall system and specific devices need to be flexible as to who can use them where and how. The whiteboard device at the CareFacility aims to accommodate system access by being available online through any device In HomeCareAlliance, the device remains with the patient, but anyone who has access to the device can access the system. Here, balances of advantages and disadvantages are obvious: The former solution of the CareFacility requires a more complicated technical setup that allows multiple devices and locations to connect, depends on Internet accessibility at each partner location, secure communication between devices, etc., whereas the HomeCareAlliance solution that is pre-installed on a single and known device. The second generic design guideline is then to:

Adopt an open design to accommodate the evolving and diverse actors, who are possibly located at different places, or nomadic.

Since neither all involved collaborators can be known in advance, nor their professional background nor which communication means are available to them, it is important that the information is not too structured or formalized, but in an open format accessible and understandable to most people. For entering information, the CareFacility system incorporates communication devices and formats such as SMS and email, and the solution in HomeCareAlliance basically operates as a free text communication device where anyone can enter information without any predefined format. In both cases, the only structuring principle for presenting information is chronology in order to enable actors to establish a (temporal) overview of the care process: The timeline in the CareFacility, and the day-to-day and discussion tabs for the HomeCareAlliance. The third generic design guideline is then to:

Provide an open format accessible and understandable to most people, so that information is not too structured or formalized.

## 6.2. Episodes are unpredictable

As episodes are unpredictable, a central challenge for supporting knotworking is to ensure that the necessary actors follow up on the patients' evolving condition or other tasks at hand. The fact that the ACM CSCW 2021 Submission

two systems allow information to be shared and plans to be commonly available, in full or partially depending on the situation at hand, contributes to pushing the care process forward, but often when an episode occurs, additional communication is necessary. Hence, the more the system and its devices are easily accessible (the mobility of the tablet in HomeCareAlliance; or the online availability of the system in CareFacility case), the better to ensure information sharing and commitment of the different actors. This is already covered by the first generic design guideline (Define flexible access to information).

The fact that episodes are unpredictable, and actors potentially work in different organizations means that collaborators often will have to interact at different rhythms. When an episode occurs, communicating synchronously, and sharing information about the patient's trajectory among collocated actors may be needed, whereas when the patient is stabilized, asynchronous communication and information sharing between distributed actors may be sufficient to take care of the patient and to be ready to identify the next episode. Therefore, the two design solutions offer a place to enter, store, and share information between collaborators that enables synchronous and asynchronous information sharing between collocated as well as distributed actors, though in different ways. For example, the care staff at the CareFacility can reach out to a patient's GP and ask for an updated medication list using the email feature in the timeline and the GP may respond when s/he has time. In the HomeCareAlliance, the app on the tablet is used synchronously when an unpredictable situation happens and several members of the care team meet face to face, make a decision about how to change the care plan, and document this decision in the patient's profile in the app. The app is used asynchronously when one care actor adds a message describing what s/he has been experiencing (for instance, if the patient does not want to eat). This message will be read by the next care actors who will respond to the message with propositions or more details, creating a "discussion" (fig3 bottom). The fourth generic design guideline is then to:

Enable synchronous and asynchronous information sharing.

#### 6.3. Work arrangements are constantly negotiated

As indicated in section 5.4, when a knot occurs, its members may not have worked together previously. As a result, they first have to understand what has been agreed on for the patient so far by other involved actors, so that they can integrate with the knot. Depending on the patient's trajectory, actors sometimes have to define and negotiate their work arrangements from scratch, while at other times, they can rely on existing arrangements. In any case, one first step is to know who is involved in the care of the patient. To face this challenge, the systems and devices in both our cases allow the various actors to become aware of who else is involved in the current episode or knot, as well as who previously has a relation to the patient or citizen if this is of relevance. In the first case, this is done by the CareFacility inviting and listing different actors, while in the second case, this is done by the patient or her entourage by keeping the list of participants updated in the tablet. The fifth generic design guideline is then to:

Provide awareness of other collaborators.

When actors who may not know each other are engaged in a knot that represents an emergency and have to negotiate their role and collective arrangements to collectively take care of a patient, a key issue is trust between actors as well as the accuracy and legitimacy of the information. In Case 1, this is ensured by the CareFacility, since they have the overall view of what is going on, which actors participate, and control access as well as who may see what. Actions and information can be attributed to identifiable actors that were granted access. In HomeCareAlliance, access is granted based on the patient allowing other actors to enter or access information, so an initial layer of trust and legitimacy also has to be built between these other actors, and here the initial layer of trust may not be enough. For example, a doctor may want to know the identity and medical specialty of another doctor before entirely trusting this person to assess patient status and prescribe treatment correctly. Hence, an additional layer of trust and legitimacy has to be built. One way to this is by making actors identifiable through name, title, photo, and contact information. Therefore, the sixth generic design guideline is to:

# Allow trust building and legitimacy.

In summary, by comparing the two different co-designed solutions in our two cases to tackle the three characteristics of knotworking, we have identified six generic design guidelines for designing information technology for knotworking. They address how information should be accessed and structured and how to handle the diversity of collaborators. (Table 3). The two rightmost columns categorize the six design guidelines thematically, three of them dealing with the information infrastructure, whereas the three others address the evolving collaborators.

Characteristics	Design guidelines	Information infrastructure	Collaborators
A dynamic	Define flexible access to information (possible and	Х	
number of	restricted at the same time)		
recurring and	Adopt an open design to accommodate the		Х
non-occurring	evolving and diverse actors, who are possibly		
actors	located at different places, or nomadic.		
	Provide an open format accessible and	Х	
	understandable to most people, so that		
	information is not too structured or formalized.		
Episodic	Enable synchronous and asynchronous	Х	
collaboration	information sharing.		
Contingent	Provide awareness of other collaborators		Х
cooperative	cooperative Allow trust building and legitimacy		X
work			
arrangements			

### Table 3. From the concept of complex knotworking to design guidelines

## 7. DISCUSSION

The six guidelines presented above in Section 6 are a first attempt to offer a design framework for computationally supporting particular collaborative situations. The identified situations revolve around collaborative activities that happen more and more frequently, particularly in healthcare, and that we characterize as complex knotworking. To our knowledge, all solutions to support knotworking that have been offered so far were organizational ones and were never accompanied by a dedicated information technology. From our point of view, the support from a dedicated technology is essential when complex knotworking is taking place. Technical solutions that have been offered to support ad-hoc collaboration in healthcare, as presented in section 2.3, focus on the patient health record and how to improve it, whereas we embrace a wider solution-space. Indeed, the design guidelines we suggest contribute to the ongoing questioning of the pertinence of the traditional client-server architectures, on which health records are built, to face modern clinical work (characterized as highly collaborative, ad hoc, nomadic, and with numerous interruptions). For example, Bardram offers the "activity-based computing" framework for hospital settings as an alternative to the traditional hospital systems [5] The goal of with the framework is to provide an infrastructure that enables clinicians to handle a large set of parallel activities while moving inside the hospital and collaborating closely with other. The five core principles of activity-based computing are: (i) the aggregation of resources; (ii) the possibility to suspend and resume an activity; (iii) the roaming of activity from one digital device to another; (iv) sharing activities among clinicians; and (v) activity awareness (ibid). The guidelines we have identified in the comparison of our two cases, confirm the relevance of the activity-based framework in home care settings. However,

whereas Bardram's framework focuses on supporting clinicians' moving about within one organization, our focus is supporting a coherent care trajectory across organizations and individuals.

More directly related to non-clinical settings, we have identified the following previous works that suggest systems that can be compared to the six guidelines we have outlined above. *The CareBinder* [16], is an augmented binder with LEDs on its cover in which all care actors can write with a digital pen. Different care actors are identified by RFID badges, and if new information concerning a care actor is entered into the binder, or if something urgent has to be done, then the related LED signals it. The CareBinder supports asynchronous information sharing, awareness of the other actors and their entries in the binder utilizing an open format accessible to most people with physical access to the binder. PressToTalk [16] is an audio-recording messages-service to support collaboration around homecare activities. The system allows different actors to exchange messages on-location. It is based on a modular architecture where each recurrent actor can have her or his own module connected to the system, which supports role-based notification of new messages. Messages can be accessed and acknowledged by holding a RFID tag close to a reader. PressToTalk provides flexible access to information through a modular design and RFID-based access-control. The modular design can also accommodate evolving, and diverse actors and the system supports asynchronous information sharing and notifications of new messages and the recordings themselves provide awareness of the other collaborators. The CareCoor system [11], is a tablet-based homecare coordination system placed in the care-receiver's home. It provides access to a shared calendar-view of the care tasks and enables family members and home care workers to exchange messages pertaining to the care of the patient as well as scheduling new care tasks. The system can also be accessed by relatives when in their own homes. The tablet-based system provides flexible access to information. Being based on a tablet and calendar-based design, the system is accessible to the involved actors and hence supports commitment in knotworking. The design provides an open format accessible and understandable to most people, where a basic calendar structure allows overview but also enables messages to be written in relation to both a specific day and activity. The calendar-based design and messages-service provide awareness of other collaborators' activities and needs.

These features offered in previous work could be considered as good candidates for parts of a system supporting complex knotworking

Regarding the design guideline on trust-building, this is aligned with the work of Corbett and Le Dantec's work on trust in civic relations where they distinguish between two layers: institutional and interpersonal trust [18]. First, citizens and patients trust the CareFacility or their GP as they belong to the institution of healthcare (first layer), and then, other care actors build interpersonal trust by identifying who they are and by interacting with each other (second layer). This design guideline also aligns with the work of Moser, Resnick, & Schoenebeck [38] who studied "community commerce" among mothers, and that found that the mothers use Facebook to buy and sell objects for a combination of reasons: They trust the other members as they belong to a closed group which is screened by the administrator (first layer of trust), and they are able to see the profile of the other members (second layer of trust). Moreover, Moser, Resnick, & Schoenebeck [38] also identified the visibility of transactions as another important factor to ensure trust, which confirms our design guidelines at a functional level (synchronous and asynchronous non-structured information sharing, open format accessible and understandable to most people, and awareness of other collaborators).

Directly related to trust-building is the issue of privacy and privacy management. We noticed in our two cases that it is not easy to balance information exchange within ongoing collaborative work with a sufficient privacy for the residents. As a result, privacy is something that is negotiated; for example, what information can be written or not on an existing semi-public whiteboard containing information about the different patients, or what can be shared in the tablet of the patient with all the care actors. Such negotiations are directly based on the trust established between individuals or related to their roles (i.e. 'I trust Carl as he seems to be a nice and 'trustworthy' person' or 'I trust what the nurse Carl tells me – he is a nurse after all and knows what is best for me'). The design solutions (the timeline-based system

at the CareFacility, and the patient's profile for the HomeCareAlliance) allow different actors to get a filtered insight into patients' individual care trajectory on a must-have-basis. Sufficient information to understand and be able to perform a required activity is shared with relevant stakeholders but not beyond that. When needed, the staff will have to collect consent from different actors (e.g., patients and relatives) prior to sharing some information. Trust is not built into the system as a function but depends on people trusting each other and on a system that enables the implementation of the agreed-upon level of privacy.

We should however remember that trust can be challenged by conflicts and different motives between stakeholders. An overview of how different stakeholders' objectives, incentives, and conflicts may challenge collaboration is given for our two cases in Table 4. The impact of an IT solution supporting complex knotworking on the management of these conflicts could be analyzed through the longitudinal observation of the deployment of such a solution. Our strong relationships with regional actors in our respective countries make us envision such a study in the near future.

Stakeholder	Role	Objectives	Incentives	Potential conflicts
Care Receiver	Subject to care	Getting well	Better health &	Disagreeing with
			life quality	treatment
Healthcare	Professional	Providing or	Service quality,	Conflicting schedules
professionals		managing care	efficiency	or procedures, scarcity
			and/or	of time
			revenue	
Informal	Informal support	Caring for	Healthy person	Disagreement with
caregivers (e.g.	and care	relatives or		quality or efficiency of
relatives)		friends, etc		treatment
External	Professional	Providing	Revenue	Non-health staff with
partners*	service delivery	various		revenue focus instead
		services		of care delivery

#### Table 4. Overview of Stakeholders

\*Such as assistive technology suppliers, transport companies, food deliveries, cleaning services, etc.

The audience for the above design guidelines goes beyond the often-involved parties in IT development projects. Complex knotworking requires to think about flexibility and long-term sustainability of IT systems that adapt to the evolution of their core users and their work practices while facilitating the integration of more ad hoc users. Indeed, as we have argued, complex knotworking entails that stable solutions are only partially possible and that new add-ons taking care of new problems will be required. There is yet little research into how to sustain IT systems beyond the project phase. However, Iversen & Dindler [30] point to maintaining, scaling, replicating and evolving as four different ways of going beyond the initial development project, and Meurer et al [37] point to a multi-dimensional space for sustainable development of IT. Kyng in turn investigates how to create and sustain alternative (healthcare) systems and, for example, describes the role an organizational entity can assume maintaining and further developing a system after an initial project end [34]. These papers point to the challenges of aligning multiple stakeholders on a long-term basis and keeping the design stable, yet open. Their frameworks are, we think, good starting points for working out how to sustain IT for complex knotworking as well, and much will depend on concrete circumstances.

The two cases presented here are similar in that they are both from European countries offering government funded, universal healthcare systems, which means (mainly) free of charge healthcare services. While there are similarities there are also differences; the CareFacility is part of the public healthcare, whereas the HomeCareAlliance gathers actors with private practices. In both cases, finding an entity responsible for sustaining the IT solutions and developing them further on is a challenge:

Presently, the CareFacility depends on municipality-provided IT solutions, whereas each GP has their own IT supplier, and for the HomeCareAlliance, a shared IT provider would yet have to be found. In a private sector-based healthcare system, the dynamics of collaboration and challenges of developing and sustaining a flexible IT system are necessarily different. Even in universal healthcare systems where individual financial interests are less pronounced and a shared interest in doing good for the patients is supported through quality systems, it can be a challenge to make healthcare professionals, such as for example doctors, invest time and effort in developing EHRs (See e.g. [48]). In this context, in addition to contributing to the discussions in the CSCW research community, our design guidelines are an attempt to influence the way IT systems are developed. In particular, we envision these guidelines as a way to empower regional healthcare agencies in Europe in their relationships with IT companies and vendors. Healthcare agencies are presently the ones most capable of enforcing suitable IT solutions that support collaboration across sectors and domains. Indeed, this is currently what we started to do in COUNTRY2, in which a law has passed that promotes cooperation among healthcare workers at different levels (municipalities, regions, hospitals). In this context, the regional healthcare agencies have created an ehealth branch to help them define and deploy IT systems. One of their central challenges is to bridge the strategic objectives of the law and their present IT systems.

## 8. CONCLUSION

In this paper, we have argued for the relevance of the concept of knotworking as a way to frame analyses of temporary, episodic collaboration between a dynamic number of actors. We assume this kind of collaboration will be more and more widespread in healthcare in conjunction with efforts to integrate healthcare services more and better across domains and settings, which will require addressing complex knotworking.

We have strived to show the strength of the knotworking concept by applying it to two different cases in two different countries and conducting a comparative analysis. Further, the comparative discussion of the two design solutions has created a better understanding of how to support knotworking, and especially complex knotworking situations in healthcare. Our increased understanding of supporting knotworking have led us to propose six guidelines for designing computer-supported knotworking.

Finally, while our arguments and design guidelines are based on two cases within healthcare, it is reasonable that our findings can be generalized and applicable for supporting knotworking outside of the healthcare domain. This claim, of course, needs to be substantiated by further studies. However, since the kind of collaboration that knotworking and complex knotworking characterize is likely to become more widespread within various domains as organizational borders become porous or dissolve, there is a challenge for CSCW to meet. We argue that knotworking and the related design guidelines can be a good way forward since it is the characteristics of the knots, rather than the application domain that is of importance.

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