Augmenting Distributed Cognition Analysis For Home Haemodialysis: From a System of Representations To Systems of Activity-Centric Interactions

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I, Atish Rajkomar, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Abstract

This thesis investigates the application of Distributed Cognition (DCog) to understand patients' situated interactions with Home Haemodialysis Technology (HHT). With the anticipated increase in home healthcare, there is a need to understand how Home Medical Devices (HMDs) should be designed so that they are patient-friendly and can be safely used in the home. This implies studying situated interactions with current HMDs and identifying the issues that patients face. Taking HHT as an example of a HMD, this thesis focuses on understanding the contexts in which renal patients interact with HHT, and their interaction strategies and issues, from a DCog perspective. DCog has been a useful theoretical framework for understanding work in clinical settings, but has not previously been applied to the study of interactions with HMDs. Data was gathered during visits to 19 patients through ethnographic observations and semi-structured interviews. 3 renal nurses, 3 renal technicians, and 1 nephrologist were also interviewed. Data was analysed by constructing the representational models of the Distributed Cognition for Teamwork framework (DiCoT) to understand the context of interactions, focusing on system activities, information flows, physical layouts, artefacts, social structures, and system evolution, and by applying the principles associated with these models to identify patients' interaction strategies and issues. This thesis brings five contributions to the study of situated interactions with HHT. Firstly, it provides an account of patients' experiences of interacting with HHT. Secondly, it demonstrates the utility of DCog as a theoretical framework for understanding interactions with a HMD such as HHT. Thirdly, it develops new theoretical principles that help to understand how people distribute cognitive processes through time. Fourthly, it develops a Contextual Factors Analysis that facilitates the analysis of complex interaction strategies. Finally, it develops an overarching approach that augments DCog analysis from considering a system of representations to considering systems of activity-centric interactions.

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List of Abbreviations

AT	Activity Theory
CF	Contextual Factor
CFA	Contextual Factors Analysis
DCog	Distributed Cognition
DiCoT	Distributed Cognition for Teamwork
DUS	Dialysis Unit System
H1…H4	Hospital 1…Hospital 4
HH	Home Haemodialysis
HHS	Home Haemodialysis System
HHT	Home Haemodialysis Technology
HMD	Home Medical Device
HS	Home System
M1…M5	Machine 1…Machine 5
SS	Society System
TS	Technology System

Chapter 1: Introduction

1.1 Problem statement: understanding situated interactions with HHT, from a DCog perspective

The goal of this research is to study patients' situated interactions with Home Medical Devices (HMDs), taking Home Haemodialysis Technology (HHT) as an example of a HMD. HMDs pose a special challenge for design, as they are used by people from various backgrounds, with varying cognitive and motor skills, in a range of situations, and in environments that are not controlled like clinical settings. Incidents with HMDs have already caused patient harm (Al-Tarawneh, Stevens, & Arndt, 2004; NPSA, 2010), and with the anticipated increase in home healthcare in the future (Lewis, 2001), there is a need to better understand how HMDs are used in practice, so that the future designs of these devices are safe and patient-friendly.

Distributed Cognition (DCog) is a theoretical framework that has been useful for understanding situated interactions in clinical settings. It has not previously been applied to the study of interactions with HMDs. However, one of the two reported studies done on situated interactions with HMDs remarks that the setting that they studied constitutes a distributed cognitive system, which gets transformed as healthcare shifts from the hospital to the home (Obradovich & Woods, 1996). This suggests that DCog may be a useful theoretical framework for understanding situated interactions with medical devices in the home as well as in clinical settings.

This thesis investigates renal patients' situated interactions with HHT, using DCog as a theoretical framework.

1.2 Contributions of this research: methodological, empirical and theoretical

The overall contribution of this thesis is the application of DCog to the study of situated interactions in Home Haemodialysis (HH), to inform the design of HHT. This overall contribution is formed by five contributions, which are in three threads of studying situated interactions with HHT: a methodological thread, an empirical thread, and a theoretical thread.

The two contributions in the methodological thread are:

- The development of an approach for doing a DCog analysis that helps to make sense of the complexity of the context of HH. This approach augments DCog analysis from a system of representations to systems of activity-centric interactions. It allows a researcher to engage with and make sense of a complex yet loosely structured setting such as HH, and it leverages the potential of DCog to understand broader situated interactions to inform system design.
- The development of a Contextual Factors Analysis (CFA) framework, which provides an analytical structure for dealing with the complexity of strategies and variability in strategies across participants, to help progress from analysis to design implications.

The contribution in the empirical thread is:

- An understanding of the contexts in which renal patients interact with HHT and of their interaction strategies and issues. This leads to an understanding of the patient experience in terms of learning to use HHT, safety during dialysis, usability of HHT, and coping with the complexity of dialysis, and leads to implications for HHT design, training and use, which could improve the patient experience.

The two contributions in the theoretical thread are:

- The development of new theoretical principles that help to understand cognitive processes distributed through time in short-term activity.
- The demonstration that cognition is distributed in HH, through people, the physical environment, artefacts, and the time continuum. This posits DCog as a useful theoretical framework for studying situated interactions in that setting, especially when the aim is to understand how safety is achieved or compromised.

1.3 Organisation of this thesis

1.3.1 Summary of the phases of this research

This research went through the following phases. First, a literature review was conducted. Based on the literature review, a methodology was formulated. This methodology was then applied in a preliminary study with 5 patients, and then adapted based on the findings of that study. Then, a main study was conducted in three phases, with 19 patients across 4 hospitals. The overall results of the main study are presented in the thesis.

1.3.2 Literature Review (Chapter 2)

Chapter 2 presents the literature review. The literature review focuses on:

1) current HMDs, the challenges involved in designing them, and safety incidents related to them;
2) empirical and methodological findings of previous studies on situated use of medical devices in clinical settings, of HMDs, and of HHT specifically;
3) DCog, a theoretical framework that has been proposed as being particularly well suited for studying healthcare socio-technical systems, and DiCoT, a structured method for applying DCog in practice.

Based on the literature review and the overall goal of this research, that is to understand situated interactions with HMDs, 5 initial research questions were formulated, which guided the earliest phases of the research:

Methodological questions

- *What methods can be used to gather data effectively and efficiently on patients' interaction strategies with HMDs and on the context in which interactions happen?*
- *How can DiCoT be used to understand patients' interaction strategies with HMDs and the context in which these interactions happen, in terms of a home healthcare socio-technical system?*

Empirical questions

- *What are the interaction strategies that HMD users adopt to cope with difficulties or to optimize their interactions, and are these strategies linked to potential safety implications or interaction design issues?*
- *What are the physical and social contexts in which patients interact with HMDs, and how do these contexts influence users' interaction strategies with HMDs?*

Theoretical question

- *How well suited is DCog as a theoretical framework for studying patients' interaction strategies with HMDs?*

1.3.3 Methodology (Chapter 3)

Chapter 3 presents the general methodology of this research that was formulated after the literature review. Based on the literature review, and available opportunities to get access to home patients, a general methodology to be used across the research was formulated, as a solution to the methodological research question: *What methods can be used to gather data effectively and efficiently on patients' interaction strategies with HMDs and on the context in which interactions happen?*

The methodology defines the 'field' for this research as being renal patients using HHT, and describes how access was gained to participants. It proposes the use of ethnographic methods to gather data, and the use of the Distributed Cognition for Teamwork framework (DiCoT) to analyse data. This methodology was then applied and adapted in the preliminary study.

1.3.4 Preliminary Study (Chapter 4)

Chapter 4 presents the findings of the preliminary study. The preliminary study was started using the initially formulated methodology, mentioned above. This study sought to address the 5 methodological, empirical, and theoretical questions formulated after the literature review, to inform the rest of the research.

The main empirical findings of the preliminary study were that renal patients do face interaction issues, and also that the broader context of use influences how patients interact with HHT.

The main methodological findings of the preliminary study were that observations tended to be opportunistic and unstructured, that interviews proved effective in eliciting incidents that patients had had during dialysis, and that video/paper diaries did not work in practice. Also, two major analytical issues were identified. The first one was that the context had to be conceptualized as consisting of several systems, instead of a single socio-technical system, to scope the DCog analysis in a structured way. The second one was that some interaction strategies were complex, in the sense that they were related to several contextual factors, which needed to be considered when reflecting on design implications. This highlighted the need to develop an analytical framework that would allow a coherent analysis of these complex strategies; this laid the foundation for the development of CFA.

The two theoretical findings of the preliminary study were, firstly, that cognition is distributed in the HH setting, socially, physically, and artefactually, and secondly, that cognition is also distributed temporally in short-term activity in HH. This suggested that DCog is a useful theoretical framework for understanding patients' situated interactions with HHT. The insight that cognition was also distributed temporally in short-term activity laid the foundation for the development of a new model of temporal structures in the main study.

At the end of the preliminary study, 5 objectives were formulated for the rest of the research, each mapping to a contribution of the research:

- Methodological Objective 1, of developing an approach for doing the DCog analysis that helps to make sense of the complexity of the context of HH.
- The empirical objective of understanding the context in which patients interact with HHT, their interaction strategies and issues, and how the patient experience of interacting with HHT could be improved.
- Theoretical Objective 1, of assessing whether a DCog approach can facilitate the understanding of patients' situated interactions with HHT.
- Theoretical Objective 2, of developing principles for understanding cognitive processes distributed through time.
- Methodological Objective 2, of developing an approach for dealing with the complexity of strategies and variability in strategies across participants, to help progress from analysis to design implications

1.3.5 DCog Analysis (Chapters 5-12)

After the preliminary study, a main study was conducted in three phases, with 19 patients across 4 hospitals. In this study, patients' interaction strategies and issues with HHT were identified using DCog as a theoretical framework. Chapters 5 to 12 present the overall results of the DCog analysis across the three phases of the main study.

Chapter 5 gives an overview of the DCog analysis. It also details the methods of the DCog analysis, and gives some background on the participants, on the different dialysis machines used by them, and on the different hospitals.

Chapter 6 focuses on the systems and activities involved in HH. It addresses Methodological Objective 1, by conceptualising the context of HH in terms of systems of activities. It also addresses the empirical objective, by presenting interaction strategies and issues related to the broader systems.

Chapters 7 to 11 respectively focus on different themes of patients' interactions with HHT: information flows, social structures, physical layouts, artefacts, and system evolution. They each address the empirical objective by presenting interaction strategies and issues related to their respective themes, and address Theoretical Objective 1 by demonstrating how cognition is distributed in that particular theme.

Chapter 12 presents a new model developed in this research, which focuses on the temporal structures involved in patients' interactions with HHT. Besides addressing the empirical objective and Theoretical Objective 1, it also addresses Theoretical Objective 2, by presenting new principles that help to understand how cognitive processes can be distributed through time in short-term activity.

1.3.6 Contextual Factors Analysis (Chapter 13)

Chapter 13 presents an analytical framework of contextual factors, which addresses Methodological Objective 2. It provides a structure for analysing complex interaction strategies, by considering the contextual factors associated with a strategy. This supports reasoning about the design implications of observed strategies, and helps to derive general insights across related strategies of different participants. In Chapters 6-12, the design implications of reported interaction strategies and issues are reflected upon at a high level, without probing deeper to uncover other factors that may be linked to the strategies and issues. Chapter 13 illustrates deeper analyses of two sets of strategies through CFA. These two sets of strategies are: optimising on time spent in the Dialysis activity, and remembering to perform certain steps. As the overall focus of this research was on the DCog analysis, CFA was applied only in the first phase of the main study.

1.3.7 The Patient Experience (Chapter 14)

Chapter 14 focuses on the empirical objective of this research, and reflects on the patient experience of interacting with HHT, in terms of four aspects of the patient experience: learning to use HHT, safety during dialysis, usability of HHT, and coping with the complexity of dialysis. Based on the results of the DCog analysis, it discusses existing design features that contribute to a positive experience, and provides recommendations that could potentially improve the experience. It also shows that the patient experience is an affair of systems, and that it may involve trade-offs amongst the four aspects.

1.3.8 From a System of Representations to Systems of Activity-Centric Interactions (Chapter 15)

Chapter 15 focuses on Methodological Objective 1 and Theoretical Objective 1. It first articulates how DCog analysis was augmented in this research to study situated interactions with HHT: by conceptualising the setting in terms of systems of activities instead of a single system, and by considering broader interactions instead of only the flow and manipulation of functional representations. It then reflects on the utility of DCog as a theoretical framework for understanding situated interactions with HHT, and posits DCog as a useful framework when the research aims to understand how safety is achieved or compromised.

1.3.9 Conclusions & Future Work (Chapter 16)

Chapter 16 concludes and reflects on possible future work.

1.4 Publications resulting from this work

The work presented in Chapter 4 has been published as:

Rajkomar, A., Blandford, A., & Mayer, A. (2012). Situated Interactions of Lay Users With Home Hemodialysis Technology: Influence of Broader Context of Use. *Proceedings of the 2012 Symposium on Human Factors and Ergonomics in Health Care* (pp. 215–219). Human Factors and Ergonomics Society.

Rajkomar, A., Blandford, A. & Mayer, A. (2013). Gathering data on patients' interactions with home hemodialysis technology. *Proc. CHI workshop 'HCI Fieldwork in Healthcare'*. ACM.

Rajkomar, A., Blandford, A. & Mayer, A. (2014). The ideal and the practical for studying patients' interactions with home haemodialysis technology. In Furniss, D., O'Kane, A. A., Randell, R., Taneva, S., Mentis, H., & Blandford, A. (Eds.), Fieldwork for Healthcare: Case Studies Investigating Human Factors in Computing Systems. *Synthesis Lectures on Assistive, Rehabilitative, and Health-Preserving Technologies*, *3*(1), 1–129. Morgan & Claypool.

The work presented in Chapter 12 has been published as:

Rajkomar, A., Blandford, A., & Mayer, A. (2013). Coping with complexity in home hemodialysis: a fresh perspective on time as a medium of Distributed Cognition. Cognition, Technology & Work, 1-12.

The work presented in Chapter 15 draws upon work done for my MSc thesis, which has been published as:

Rajkomar, A., & Blandford, A. (2012). Understanding infusion administration in the ICU through Distributed Cognition. *Journal of biomedical informatics*, *45*(3), 580–90.

Chapter 2: Literature Review

2.1 Introduction

The literature review consists of four parts. The first part (section 2.2) describes current HMDs, details on programmable HMDs, including HHT, and justifies the motivation for doing this research. The second part (section 2.3) reviews previous field studies that have been done on the use of medical devices in clinical settings, and on the use of medical devices in the home, including HHT. The third part (section 2.4) introduces DCog and one approach to applying it to the study of situated interactions, DiCoT. It then reviews previous studies that have applied DCog in healthcare, in home healthcare, and in the home more generally. The fourth part presents a discussion of the reviewed literature and the work proposed for this research (section 2.5).

2.2 Home Medical Devices

This section describes the rise of home healthcare (section 2.2.1), some of the HMDs currently in use (section 2.2.2), programmable HMDs (section 2.2.3), HHT (section 2.2.4), challenges for the design and use of HMDs (section 2.2.5), and safety incidents involving HMDs (section 2.2.6). Based on these, a motivation for studying the use of HMDs in their real context of use is presented at the end of this first part (section 2.2.7).

2.2.1 The rise of home healthcare

In the UK and in the USA, patients are increasingly taking responsibility for their own health management in the home. This is being made possible by advances in medical devices, products and technologies, and the US Food and Drugs Administration describes home care systems as the fastest growing segment of the medical device industry (Lewis, 2001). The shift from hospital-based healthcare to home healthcare is due to a number of reasons: reduced healthcare costs, increased convenience for patients, possibilities for physicians to intervene in earlier stages of illnesses through increased patient (self) monitoring, earlier discharges from acute care settings to home while patients may still need daily care, and more elderly people wanting to live independently. Already, a broad range of health services are being delivered at home to different types of patients.

Chronically ill infants and children are receiving sophisticated medical treatment in their familiar and secure home environment. Many younger adults who are disabled or recuperating from acute illnesses are opting for home care, whenever possible. Terminally ill adults and children are also being cared for at home. The next section looks at the HMDs currently in use.

2.2.2 Types of HMDs

The systems that make home care possible consist of a range of devices, such as smart devices that can "think" for themselves, customized wearable devices, and wireless internet-linked systems, all expected to deliver convenient, user-friendly, intelligent health care in the home (Lewis, 2001). Examples of such HMDs are: blood pressure monitors, glucose meters, assisted living and telecare products, suction machines, ventilators, nebulisers, physiological monitors, infusion pumps, insulin pumps, enteral feeding pumps, and HH machines.

There are more types of HMDs, and the exact definition of what constitutes a "home medical device" is not clear, considering factors such as whether the device is meant to be used by professionals only or by lay people as well, and whether the device was designed with the explicit intention of being used in the home environment or not (Gupta, 2007). This research is particularly concerned with interactive, programmable HMDs that are used by patients for medical therapy, described in the next section.

2.2.3 Programmable HMDs

Some HMDs are interactive and require users to program settings when they are used. Based on the literature review and consultation with community healthcare practitioners, two main programmable HMDs that are used in the UK currently are infusion pumps and dialysis machines. Infusion pumps are devices that deliver fluids into a patient's body in a controlled manner. They are used to deliver nutrients or medications such as hormones, antibiotics, chemotherapy drugs, and pain relievers. Users of infusion pumps need to program a combination of parameters, which typically include the infusion rate, the infusion duration, and sometimes the volume to be infused. Dialysis machines are used to filter a patient's blood to remove excess water and waste products when the kidneys are damaged, dysfunctional, or missing. Users of dialysis machines typically need to program the dialysis duration and the volume of fluid to be removed from the patient. These devices include other interactive features such as alarms, which prompt the user to react to certain events. In this research, initially an attempt was made to study the use of both of these devices. However, as the research progressed, the initial opportunities to study the use of infusion pumps got cancelled, and from then onwards this research focused on HHT. The next section focuses on HHT.

2.2.4 Home Haemodialysis Technology

Home dialysis was first developed 40 years ago, as a means of treating more patients suffering from kidney failure with the limited funds available. Studies showed that the treatment worked well, that it improved both mortality and morbidity, and that it provided the best quality of life and other benefits for dialysis patients (Blagg, 2005).

There are two main types of home dialysis: peritoneal dialysis and haemodialysis. Peritoneal dialysis involves using the patient's peritoneum lining in the abdomen (as a membrane) to clear toxic metabolites from the patient's blood (Segen, 2006). Haemodialysis uses a dialyser, a special filter, which is connected to a machine, to clean the patient's blood. Figure 2.1 below shows some of the main components in a typical haemodialysis circuit (MAA Medicare Kidney Charity Fund, Malaysia, n.d.). During treatment, the patient's blood travels through tubes into the dialyser. The dialyser filters out wastes and extra fluids from the blood into a dialysate solution, through diffusion and osmosis. Then the newly cleaned blood flows through another set of tubes back into the patient's body. Pressure sensors monitor the pressures of the flow at different points in the circuit, and alarm in case a pressure is out of specified safety limits. An air detector checks for air bubbles and alarms if air bubbles are detected in the cleaned blood flowing back to the patient. Some machines have a pump to inject heparin, an anti-coagulant, into the circuit, so that blood does not clot in the circuit.

Figure 2.1: A haemodialysis circuit (Source: MAA Medicare Kidney Charity Fund, Malaysia, n.d.)

The treatment can be done by a nurse in a hospital or satellite dialysis unit, by a patient or carer in a satellite unit, or by a patient or carer in the home. The treatment is complex, and consists of many steps which, in summary, involve the preparation of the patient (e.g. needling), the preparation of the machine (e.g. cleaning and disinfecting), recording physiological measurements, programming parameters for a session, starting dialysis, attending to alarms and patient reactions, and terminating the dialysis session. During dialysis, the patient is usually confined to a reclining chair or couch, or their bed. Appendix A section A.1 elaborates on the medical background of HH.

Blagg (2005) states that some advantages of HH are: it encourages patient independence, responsibility and confidence; it gives freedom from the dialysis centre, eliminating the need to travel there three times a week, and enforces socialization; it allows the patient to set their own flexible scheduling, increasing comfort and convenience; it reduces the risk of infection; and it costs significantly less than dialysis in the centre. The disadvantages are: the need for space for the equipment and to store supplies; the need for help from a family member or other person; the need for modifications of domestic plumbing and electricity; increased utility bills; and a general impact on the family (Blagg, 2005). The next section elaborates on the challenges for the design and use of HMDs.

2.2.5 Challenges for the design and use of HMDs

Gupta (2007) lists a number of challenges associated with the design and use of HMDs, that mostly relate to the fact that medical device companies have traditionally been designing products for use by professionals in clinical settings. Firstly, some medical devices that were not designed for home use are being used by patients and their carers in the home environment. Also, it has been found that the majority of medical devices that are now used in the home environment actually started off as a professional piece of equipment. A number of these devices have the same technologies as their professional versions, and are simply scaled down versions of their professional types.

Secondly, healthcare professionals and patients are very different groups of medical device users. Healthcare professionals are usually trained, have some degree of experience in medical device use, and are generally experienced at overcoming device limitations and problems. On the other hand, the users of HMDs include people of all age, people with various disabilities (e.g. physical, perceptual, cognitive disabilities) and impairments (e.g. limited vision, impaired tactility and hearing loss), and people suffering from different conditions and diseases. They may not have adequate education and training in device use. In addition, they may be experiencing trauma and stress being ill. A study conducted with a so-called “simple” blood glucose meter proved that medical devices that appear trivially easy to use for professional users may not be quite that easy for lay-users and there may be many opportunities for lay users to make errors (Rogers, Mykityshyn, Campbell, & Fisk, 2001). A related point, reported by Lewis (2001), is that consumers of HMDs have difficulty understanding instructions provided with devices: most instructions are written for healthcare professionals. Another factor that probably slows down users in learning how to use HMDs is the absence of structures that facilitate social learning. Randell (2003) notes that clinicians appropriate technology and develop strategies for coping with it within specific communities of practice. In contrast, Brown & Duguid (2000) highlight that domestic users of information technology do not have access to the peer support and social learning experiences that workplace users do. We can draw a parallel and infer that HMD users may also have limited opportunities for social learning.

Thirdly, the home environment is devoid of the safety and support systems found in clinical settings; clinical settings are usually controlled in that the infrastructure supports 'proper' and 'ideal' use of a device. The home environment can differ from the clinical setting in various aspects such as: not having as much space to manoeuvre or to properly use some medical equipment; not having adequate electrical wiring to handle the correct voltage for various types of durable medical equipment; medical devices being subject to electromagnetic interference from other electronic equipment, such as microwave ovens, video game systems, and security systems; the presence of children and pets that can interrupt medical care; patients/carers lacking supplies and the ability to properly sanitize and sterilize medical equipment, or to safely dispose of the bio-hazardous waste created by medical devices. Some other challenges mentioned by Gupta (2007) are: the higher safety concerns associated with HMDs than with any other home products, because of the more serious consequences that the incorrect use of HMDs can have; the need to "design for misuse", by predicting potential misuses and designing them out, which is harder to do than for clinical settings; and the little opportunity that exists for learning by trial with HMDs – e.g. in the case of an infusion pump, users may not get a chance to use their device at all until they are required to use it in a situation where an error could have serious consequences, and some devices are meant for single use, meaning that using them for a trial would invalidate them for re-use. Obradovich & Woods (1996) present another type of challenge posed by HMDs. They discuss how, in their study, the use of an automated infusion device in the home changed how information about the effects of therapy was gathered and distributed to the people responsible for problem recognition and therapy decisions. That information was critical for modifying the therapy and for early recognition of problems. They state that the "opaque system image" presented by the infusion device and the opportunities for mis-operation created by poor interface design impaired this distributed therapy system's ability to detect potential problems. Lewis (2001) remarks that, as technological developments become more complicated, so do the requirements for their design to ensure that they can be used safely and effectively in the home. If these requirements are not met, HMDs can cause patient harm; such incidents have been reported in the past, and are discussed in the next section.

2.2.6 Incidents with HMDs

Incidents with medical devices that cause patient harm, and even death, occur in the hospital, and have been reported to occur in the home as well. A report by the UK National Patient Safety Agency attributes 4 home patient deaths in 2009 to over-infusion through an ambulatory syringe driver, which happened because of confusion between two look-alike pump models (NPSA, 2010). Another study which reviewed the home and hospital medical device incidents in the U.S. Food and Drug Administration's Manufacturer and User Facility Device Experience Database (MAUDE) for the period 1997 to 2002 reported that 108 fatal medical device incidents happened in the home, with interactive devices such as haemodialysis machines, ventilators and glucose meters (Al-Tarawneh, Stevens, & Arndt, 2004). For home healthcare to be a safe and smooth experience, HMDs need to be designed with the requirements and constraints of the home environment in mind, and with an understanding of how medical devices are actually used in practice in that environment. The next section presents the motivation for studying user interactions with HMDs.

2.2.7 Motivation for studying user interactions with HMDs

The fact that fatal incidents have already occurred with HMDs, coupled with the anticipated increase in home healthcare in the near future, makes the improvement of the safety and usability of these devices an urgent priority. To make these improvements, interactions between users and HMDs in the real context of use need to be understood. Laboratory studies only are inadequate for this purpose, as, in the real world, device users do not always perform tasks as prescribed. Instead, they often employ strategies that take advantage of the physical and social environments to optimise their tasks, and develop workarounds to cope with difficulties faced while interacting with technology. Kaufman et al. (2003) remark that there is very little evaluation research on patient populations using home health care technologies, and refer to Vicente's (1999) argument that the greatest threat to the effective and safe use of complex technological systems is events that are unfamiliar to users and that have not been anticipated by designers. They state that field research is needed to address a critical gap in knowledge regarding the use of technology by populations such as elderly chronic-care patients. This first part of the literature review established the need to study interactions with HMDs in their real context of use. The second part reviews studies that have studied the use of medical devices in their real context of use.

2.3 Studies on Situated Use of Medical Devices

This part of the literature review first presents the need for situated studies (section 2.3.1), and then presents the literature on situated use in three sets: studies of medical device use in clinical settings (section 2.3.2), studies of medical device use in the home (section 2.3.3), and studies of HHT use (section 2.3.4). Because this research focuses on interactions with medical devices specifically, as opposed to more general home care or home healthcare, the literature review focuses on studies of interactions between users and medical devices that are used for medical therapy; studies of broader assisted living systems, such as those of the Mobilising Advanced Technologies for Care at Home project (MATCH) reported in Turner (2012), are not discussed.

2.3.1 The need for situated studies

To understand how HMD users interact with the devices in practice, with the aim of making design improvements that increase the safety and usability of these devices, studies on the situated use of the devices are required. These allow one to observe the complexities of the environment in which user-device interaction takes place, the messy details of the work, the difficulties faced by users, and the strategies adopted to cope with the difficulties. Nemeth, Cook, & Wears (2007) argue that the messy details of the work of healthcare practitioners consume more of their cognitive resources than do the domain semantics, and that studying these details allows the differentiation between “work as performed” and “work as prescribed.” They recommend that one should search for workplace conflicts, complexities and uncertainties, and investigate how people cope with them, with the aim of exposing strategies and judgments, so that the robustness of these can be assessed. Essentially, the cognitive elements of work can be discovered only empirically by the study of work in its natural setting (Hutchins, 1995). The next section summarises the studies that have been done on the use of medical devices in their natural clinical settings.

2.3.2 Studies on the Situated Use of Medical Devices in Clinical Settings

Four observational studies that focus on understanding how users interact with medical devices in clinical settings are:

- the study of interactions between nurses and medication administration devices (Carayon et al., 2005). Carayon et al. (2005) conducted observations and interviews of nurses' interactions with medication administration devices across nine different inpatient units of a hospital, and found that nurses employ a broad range of strategies for performing the same task.
- the study of interactions between anaesthetists and physiological monitoring devices (Cook & Woods, 1996). Cook & Woods (1996) conducted observations and interviews of anaesthetists' interactions with newly introduced physiological monitoring devices in two operating rooms, and found that anaesthetists employ "system tailoring" and "task tailoring" strategies to cope with "clumsy automation" from technology.
- the study of medical device customization and appropriation by nurses (Randell, 2003). Randell (2003) conducted observations and interviews of nurses' interactions with technology in three intensive care units, and found that nurses develop strategies to cope with limitations of technology.
- the study of interactions between anaesthetists and device alarms (Seagull & Sanderson, 2001). Seagull & Sanderson (2001) conducted observations and interviews of anaesthetists' interactions with device alarms during different phases of surgery for different types of surgical procedures, and found that users interact with the same device in different ways depending on the precise medical context.

The next three sections present the empirical insights from these studies, the methodological insights from these studies, and my reflections on these insights and implications for this research.

2.3.2.1 Empirical insights from studies on the situated use of medical devices in clinical settings

Previous observational studies in clinical settings show that clinicians experience difficulties while interacting with medical devices, and that they develop strategies to cope with these difficulties, whether these strategies were intended by designers or not (Cook & Woods, 1996; Randell, 2003). There can be a broad range of strategies employed by users for performing the same task (Carayon et al., 2005), and in some cases, users interact with the same device in different ways depending on the precise medical context (Seagull & Sanderson, 2001). The benefits of uncovering these user strategies are that: firstly, some user strategies point to design deficiencies, highlighting implications for design (Cook & Woods, 1996; Randell, 2003); and secondly, some user strategies have potential safety issues, and can generate subtle vulnerabilities, or in some cases lead to failure modes (Carayon et al., 2005; Cook & Woods, 1996; Randell, 2003).

Cook & Woods (1996) and Randell (2003), between them, discuss the following types of strategies adopted by users: 1) overcoming limitations, e.g. removing and reinserting the battery of a vital signs monitor to reset the count of use when the device is urgently required, because after every 50th use the device prompts the user to change the batteries; 2) pen and paper adaptations to devices and to manuals, e.g. attaching post-it notes to devices to detail how to use them and to ensure everyone knows about changes to the way a device is to be used, and rewriting of manuals, adapting the language and removing unnecessary details to make them easier to understand; 3) changing the procedures for using the technology, e.g. delivering the drug heparin through a separate syringe driver, rather than through a hemofiltration device as stipulated by the manufacturer of the device; 4) modifying the system in ways that go beyond those contemplated by the system designers to make it compatible with the cognitive strategies of users, e.g. users developing their own window configuration for displaying blood pressure on a physiological monitoring device and calling that window to the screen during initialization every morning, because the default display configuration was unsuitable for supporting their task of tracking changes in blood pressure; 5) users augmenting their tasks to accommodate constraints imposed by the technology, e.g. users zeroing a blood pressure channel on a new physiological monitoring device through a series of screen activations across a complex menu space, compared to the physical button press required on the predecessor device.

The need for these strategies arises from the interaction between device characteristics and the tasks confronting the user; strategies, and their effects, cannot be predicted from the characteristics of the device only – they need to be discovered by observation in the field (Cook & Woods, 1996). Clinicians view these strategies as necessities, to provide adequate patient care, even when violating manufacturer guidelines, and feel it is up to them to get the technology to work in the way they want (Randell, 2003). Randell (2003) points out that medical work is not necessarily a sequence of individual, formally rational decisions, and that new situations require nurses to develop new strategies, analogous to the way that new patients produce new problems. Also, she states that these user strategies are not simply ad-hoc, unquestioned violations of a single individual, but are carried out within a specific community of practice.

Regarding the impact of advanced technology on practitioner performance, Cook & Woods (1996) state that it increases requirements for memory, knowledge, and attention, and they highlight that practitioner performance is sensitive to the precise nature of the representation of data. They argue that evaluations of technology based on average performance over long periods will not indicate the real impact of technological factors on expert human performance at high-workload times, as it is in high workload times that multiple demands on attention are likely to interact with automation features and produce degraded practitioner performance. Seagull & Sanderson (2001) summarise the overarching problem as being how to design information and match it to the real-time cognitive and perceptual needs of device users. The next section reviews the methodologies of these studies.

2.3.2.2 Methodological insights from studies on the situated use of medical devices in clinical settings

The major strengths of an observational methodology are the ability to collect data on the tasks actually carried out as opposed to prescribed procedures and manuals (Carayon et al., 2005), and the generation of rich, detailed data (Carayon et al., 2005; Randell, 2003; Seagull & Sanderson, 2001). Randell (2003) remarks that the level of detail of the data she gathered allowed for an opening of a discussion that fundamentally questioned the preconceptions about the organization of work, rather than just the provision of specific design recommendations for specific systems. These studies used observational methods such as time study and flow process charting (Carayon et al., 2005), process-tracing, to construct behavioural protocols (Cook & Woods, 1996; Randell, 2003; Seagull & Sanderson, 2001), and cognitive task analysis (Cook & Woods, 1996). Observation sheets were used to record notes in all of the four studies, and later transcribed. For most of the studies, special observation sheets were developed during the first few observations (Carayon et al., 2005; Cook & Woods, 1996; Seagull & Sanderson, 2001). Carayon et al. (2005) report that the observers in their study were "complete observers" who did not participate in any way in the process being observed, and Randell (2003) reports that her observations were unobtrusive. Randell (2003) conducted her observations during both of the two nurse shift periods, to understand how work varied over the day.

Besides observations, researchers conducted interviews with participants to: improve their understanding of particular events in a complex setting (Randell, 2003); supplement observation data (Cook & Woods, 1996); ask for clarifications on actions performed by participants or devices that appeared out of the ordinary interaction (Carayon et al., 2005); and to conduct post-operative reviews with participants to validate observation data (Seagull & Sanderson, 2001). These exchanges with participants happened either when auditory alerts indicated that an error had occurred (Carayon et al., 2005), or during a particular phase of an observed intervention (Cook & Woods, 1996), or informally during coffee breaks and quiet moments (Randell, 2003). However, the essential element of the data gathering remained the observations – to rely on methods such as interviews would not only neglect the complex relationship between what people say and what they do, but would also be limited by the researcher's preconceptions, which determine which questions are asked (Randell, 2003). Researchers also took other measures to deepen their understanding of the context, such as attending training sessions on the devices (Cook & Woods, 1996; Randell, 2003) and attending meetings of nurses and doctors (Randell, 2003). To help make sense of observation data, they also consulted system manuals (Cook & Woods, 1996) and other medical documents related to the procedures being observed (Seagull & Sanderson, 2001). Additionally, Carayon et al. (2005) designed a pump programming process flow diagram to help follow and record the observed pump programming steps and alarms detected. Seagull & Sanderson (2001) reflect that, though their data collection mechanism, which combined different sources, provided a comprehensive perspective on the procedures observed, audio-visual recording would have improved the richness of data. They were limited to focusing on events denoted by auditory alarms; audio-visual recording would have allowed them to capture events denoted by visual alarms as well.

A common thread in these studies is the collection of data about the broader context in which interactions happen, ranging from collecting data about the environment but still focusing only on the medication administration element of the nursing job on one end (Carayon et al., 2005), to collecting data for general activities and not confining observations to strictly the surgical procedures of interest (Seagull & Sanderson, 2001), to following a complete bottom-up approach and recording as many details as possible on the other end (Randell, 2003). Randell (2003) argues that a bottom-up approach allows a researcher to discover phenomena, rather than having preconceptions of what to look for. Through this approach, the topic of customization emerged from her observations, and she was able to gain an understanding of how the work of customisation fitted in amongst the nurses' general concerns and daily routine, how the various groups of nurses viewed and gave meaning to the situations that arose, and how they chose to pay attention to some things and not others. Another point worth noting is that researchers used availability samples, and not probability samples, most probably due to limited population sizes. Seagull & Sanderson (2001) selected surgery cases on the basis of their availability during the period of observation and their fit to the chosen categories of surgical procedures. Also, they chose the surgical procedures to sample based on a pilot investigation and in consultation with anaesthesia professionals, highlighting the importance of these in planning studies. The next section presents my reflections on these studies and the implications for this research.

2.3.2.3 Reflections on studies on the situated use of medical devices in clinical settings and implications for this research

Clinicians experience difficulties while interacting with devices in clinical settings, and it is reasonable to assume that home healthcare practitioners, lay carers, and lay patients also face difficulties when interacting with similar devices in the home, despite the significant differences between the two environments. The strategies that users adopt to cope with these difficulties and inherent device design deficiencies can lead to safety issues. This research attempts to explore the different types of strategies adopted by users when using HMDs and any interaction design deficiencies of the devices, to identify related safety implications. As these situated strategies and their effects cannot be predicted from the device characteristics alone, this research should employ an observational methodology for data gathering, similar to the studies discussed above. An observational methodology will allow gathering of rich detailed data about how HMD users interact with the devices in practice, and allow an understanding of how such interactions fit into the broader life patterns of users. This section reviewed a set of studies on the situated use of medical devices in clinical settings. The next section reviews a set of studies on the situated use of HMDs.

2.3.3 Studies on the Situated Use of HMDs

Two studies on the situated use of HMDs that report actual interaction strategies of users are: an observational study on the level of user-friendliness of four different home care technologies (Lehoux, 2004), and an observational study on the use of infusion devices in the home for pre-term labour management (Obradovich & Woods, 1996).

Lehoux (2004) conducted observations and interviews to understand how the level of user-friendliness of four different home care technologies influence their integration into the private and social lives of patients. The four technologies were: intravenous therapy, parenteral nutrition, oxygen therapy and peritoneal dialysis. Lehoux (2004) found that home healthcare technology constrains and restricts the social lives of patients and carers, and this in turn influences their acceptance of the technology.

Obradovich & Woods (1996) conducted observations and interviews to examine users' interactions with an infusion device in the home. They identified deficiencies in the interface design of the device in the context of pre-term labour and found that users developed "tailoring strategies" to protect themselves from failure. The next three sections present the empirical insights from these studies, the methodological insights from these studies, and my reflections on these insights and implications for this research.

2.3.3.1 Empirical insights from studies on the situated use of HMDs

Obradovich & Woods (1996) identified classic HCI deficiencies in HMDs, such as: complex and arbitrary sequences of operation; different operating modes intended for different contexts; ambiguous alarms; potential for users getting lost in the interface; and poor feedback on device state and behaviour. These deficiencies created the potential for erroneous assessments and actions that could contribute to critical incidents and outcome failures. Lehoux (2004) found broader deficiencies, in terms of technology not fitting neatly in the home and not meeting the diverse and changing needs of chronic patients, e.g. a room getting uncomfortably hot due to oxygen therapy. These studies also identified strategies that users developed for coping with design deficiencies, for overcoming limitations imposed by the devices, and for protecting the larger system from failure. For example, Obradovich & Woods (1996) found that users modified or eliminated procedures for using the infusion device, developed patient guides, and used a paper clip to close the pages of documentation that discuss the delivery mode of medication not being used. Lehoux (2004) found that one patient had developed her own technique for preventing the formation of air bubbles in infusion tubing, that some oxygen therapy patients had an extra set of tubing so they could use another floor or sit outside, and that one peritoneal dialysis patient planned to have an evacuation system installed so that he could dispose of waste solution without going to the toilet. Obradovich & Woods (1996) identified potentially hazardous side effects associated with some of the strategies, and they illustrate the brittleness of the strategy of relying on a paper clip to ensure that instructions for the relevant delivery mode are followed – the paper clip may be lost or may be inadvertently placed on the wrong pages. Lehoux (2004) suggests that patients who seemingly accepted home care technology out of despair, but then later regretted their choice, tended to adopt sub-optimal routines over time.

Lehoux (2004) found that although each technology provided patients with relative autonomy from the hospital and contributed to their health, none of them were perceived as truly user-friendly. User acceptance was shaped by different kinds of anxiety, such as the alarm system of the programmable pump going off too easily, and was also closely linked to competence – older patients felt less comfortable with the electronic components of the infusion pump, and chronic patients seemed keener to master technical aspects. Patients seemed more likely to develop competence for parenteral nutrition and peritoneal dialysis, because of limited alternatives in these cases, while intravenous therapy patients were generally passive or even submissive to the technical aspects of the technology. The patient who developed her own technique for preventing the formation of air bubbles in the infusion tubing was technically confident. Some patients were not able to read messages on the digital screen due to poor eyesight, or limited English linguistic skills, or illiteracy, and relied on their memory or made informed guesses, illustrating the varying cognitive and physical capacities of home healthcare technology users.

Home healthcare technology considerably changes the therapy system, and, from a different perspective, considerably impacts the social lives of patients. Obradovich & Woods (1996) found that the introduction of the infusion device and the shift from in-hospital to in-home control of pre-term labour changed the roles and responsibilities of the different participants in the therapy system. A new component of supervisory control was introduced into the nursing function as traditional nursing functions were delegated in part to the patients, who became active participants in their therapy. How the perinatal service nurse gathered information about the impact of therapy and how the nurse adjusted delivery of medication changed as well. They conclude that making technology a team player requires designing the distributed system of human and machine agents that manages the activity in question. Lehoux (2004) found that although each home care technology studied provided patients with relative autonomy from the hospital and contributed to their health, it imposed significant constraints on patients and their carers; it restricted their social activities and their mobility, through social stigmatization and technical barriers. There is therefore a strong link between patients' interactions with HMDs and the social context in which these interactions happen, supporting the argument of Blandford et al. (2009), that the broader context in which interactions happen needs to be studied, because even a focused interaction between one person and a particular system happens within a broader context that includes other people, other systems and other interactions. To show the value of contextual studies in informing design, Obradovich & Woods (1996) propose a more effective representation of device activity, which shows actual administrations against the therapy plan. This would support users in detecting deviations from the plan. The next section reviews the methodologies of these studies.

2.3.3.2 Methodological insights from studies on the situated use of HMDs

Blandford, Adams & Furniss (2009) state there is an urgent need not just to conduct evaluations of healthcare systems but also to better understand the range of possible approaches to evaluation, their costs and their benefits. Reflecting on the lack of well-developed methods for data gathering in the home, Blandford et al. (2009) highlight that the investigation of appropriate modes of data gathering will also be exploratory, working with participants to establish what works best for them as well as what yields the most reliable and relevant data. Lehoux (2004) adopted a technology-in-practice perspective, which depends on qualitative in-depth investigation of what technologies do and help achieve in the daily life of patients. They used a framework that illustrates how technical dimensions (weight, functionality, complexity) influence user acceptance, how human dimensions (self-image, cognitive resources, social stigma, pain) influence user-competence, and how the technical and human dimensions are affected by the setting (institutional, private, or public). They were guided by the approach of symbolic interactionism, which focuses on how individuals, through regular interactions, develop shared meanings and conceptualise, perceive and understand the role of technology. It helped them in identifying how patients and caregivers anticipated and defined the contributions and responsibilities of each other. Lehoux (2004) recruited participants through primary care organisations and hospitals that deliver home care in the region of Montreal, Canada. They used a sampling strategy that included participants of varying socioeconomic status, gender, and age, as according to them, these variables were likely to affect how patients and their carers adapt to the use of technology. Ultimately, due to the inclusion of four different interventions, they could not explore the influence of these variables. However, the inclusion of different interventions put a broader perspective on the research problem.

Previous studies of HMDs combined and triangulated several sources of data. Lehoux (2004) had three sources of data: interviews with patients, interviews with carers, and direct observations of nursing visits. Obradovich & Woods (1996) conducted three kinds of investigations: interviews with nurses about how nurses and patients used the device; bench tests that explored device behaviour, representations of states and activities, and control sequences; and observations of nurses programming the device. Obradovich & Woods (1996) conducted the investigations in an iterative and intermixed fashion, with one type of investigation informing or setting the stage for another. Blandford et al. (2009) outline a plan of using a combination of diary studies, interviews and video recording to capture minor incidents, working with patients and carers as partners in understanding and critiquing the design of the systems that they use. Regarding data analysis, Lehoux (2004) drew tables to summarise observations from the three sources of data for the four technologies. In analysing the tailoring strategies that users had developed, Obradovich & Woods (1996) used the experience of one of the authors, who had used this device as a patient when the system first went into use in that region of the country, as a baseline. Additionally, Obradovich & Woods (1996) point out that due to lack of organizational support, their ability to collect and report more kinds of data, e.g. the analysis of actual incidents and the observation of patients or prospective patients during training and actual device use, was limited.

Blandford et al. (2009) foresee that, for understanding details of users' experiences with healthcare technologies in the home, interviews will not be sufficient; observational work will be required to see how technology integrates with the home and makes patients feel more confident in a familiar setting. However they emphasise that observational work in homes presents a special research challenge in terms of the efficiency, effectiveness, privacy and ethical issues of data gathering and analysis. Lehoux (2004) used an observation guide to record descriptive notes during visits, and wrote up a structured summary of key events after the visit. They mention that direct observations allowed a better understanding of how patients were educated about and supported in the use of technology. Lehoux (2004) and Obradovich & Woods (1996) used interviews differently. The former used biographical interviews to examine coping strategies, and to elicit how patients and carers perceived the technology and how their lives were transformed because of technology use. They sought to cover the themes of the technology-in-practice framework. The latter used interviews with nurses to specifically examine how users learnt to train, inform, and proceduralise tasks so that the infusion device could be used despite its HCI deficiencies. In another study, Kaufman et al. (2003) evaluated the usability of a telemedicine system in patients' homes by recording video data of the participants and of the system's screen displays. They analysed the video data at different levels of granularity to understand participants' interactions with the system. The next section presents my reflections on these studies and the implications for this research.

2.3.3.3 Reflections on studies on the situated use of HMDs and implications for this research

Previous studies of HMDs confirm that users of these devices experience difficulties while interacting with them, and that some technologies do not fit well into the home environment. This research aims to further explore the coping strategies of users and possible interaction design deficiencies of HMDs, and will attempt to understand how HMDs fit into the broader context of the home environment. The shift from the hospital to the home changes the distributed system of the therapy. This research will explore the distributed systems in which interactions with HMDs happen, and the roles HMDs play in such systems. Home healthcare technology constrains and restricts the social lives of patients and carers, and this in turn influences their acceptance of the technology. User acceptance, user competence, and interaction strategies are linked to each other: user acceptance of home healthcare technology influences the strategies employed by users for interacting with the technology – users with lower acceptance tend to employ sub-optimal routines over time; user competence influences the strategies used – technically confident users tend to develop advanced strategies; and user competence influences user acceptance – users who feel competent with the technology tend to accept it more than those who do not. Since interaction strategies seem to be influenced by how well the technology fits into the social settings in which patients are evolving, this research needs to understand patients' interactions with HMDs in the broader social context in which these interactions happen.

Reflecting on the approaches used by the studies discussed above, this research should use an observational approach in an exploratory way, considering what works best for participants and what yields data effectively and efficiently, and the adaptations that need to be made to deal with ethical and privacy issues. Different sources of data should be combined: audio-recorded interviews with community practitioners, with patients, and with carers; direct observations of nursing visits and of patient interactions with devices, with the help of observation guides; video recording done by the researcher or by patients and carers; analyses of device behaviour through bench tests and manuals; and diaries kept by patients and carers. The next section focuses on studies on the situated use of HHT.

2.3.4 Studies on the Situated Use of HHT

Considering both satellite unit haemodialysis and HH, no reported study focused on describing the contexts in which nurses/patients interact with HHT, or on reporting actual strategies employed by nurses/patients during interactions with the technology. This thesis aims to make a contribution in this direction. Some previous studies considered human factors more generally in HH: Wong et al. (2009) focused on understanding patients' experiences of learning to self-care for nocturnal home haemodialysis; Cafazzo et al. (2009) investigated patient-perceived barriers to the adoption of nocturnal home haemodialysis; and Cafazzo et al. (2010) investigated patients' perceptions of remote monitoring for nocturnal home haemodialysis. The findings of these studies will be discussed in subsequent chapters. Whilst these studies focused on specific aspects of the patient experience, this research aims to understand the patient experience more broadly, in terms of the contexts in which interactions happen and of a broad range of interaction strategies and issues.

This second part of the literature review presented empirical insights from previous studies of situated use, in terms of strategies that medical device users adopt to cope with interaction issues. It also presented the methodologies that these studies employed. The third part of the literature review presents the DCog theoretical framework, which can be used to guide studies of situated use.

2.4 Distributed Cognition

This part of the literature review describes DCog (section 2.4.1), and then describes DiCoT (section 2.4.2). Then, the argument for taking a DCog approach when studying healthcare work is described (section 2.4.3). The subsequent sections then present summaries of the application of DCog: in the healthcare domain (section 2.4.4), to the study of medical device use in clinical settings specifically (section 2.4.5), in the home healthcare domain (section 2.4.6), and to the study of HMDs specifically (section 2.4.7). Then, the distribution of cognition in the home is discussed (section 2.4.8). Lastly, a reflection on previous DCog studies and the implications for this research is presented (section 2.4.9).

2.4.1 Distributed Cognition Theory

DCog is an approach to understanding the organisation of cognitive systems, which considers the whole system as a cognitive unit, encompassing people and materials in the environment, rather than considering solely the individual's cognition (Hutchins, 1995). It refers to a perspective on all of cognition, rather than a particular kind of cognition, and is distinguished by two related theoretical principles (Hollan, Hutchins, & Kirsh, 2000).

The first principle, pertaining to the boundaries of the unit of analysis for cognition, stipulates that cognitive processes should be looked for, irrespective of physical location, on the basis of the functional relationships of elements that participate in the process. Traditional views of cognition, on the other hand, consider the boundaries to be those of individuals. According to DCog, a system can reorganize itself to bring subsystems into coordination to achieve different functions. The second principle, concerning the mechanisms that take part in cognitive processes, states that a larger class of events should be looked for, such as the manipulation of external objects and the traffic of representations among actors, apart from the manipulation of symbols inside individual actors. Traditional views of cognition tend to consider only the latter. On top of providing extra memory to the same processes that operate on internal memories, the physical environment presents opportunities to reconfigure the distributed cognitive system to take advantage of a different combination of internal and external processes.

When these principles are applied to the observation of human activity, three kinds of distribution of cognition are seen: distribution across the members of a social group, distribution among internal and external (material or environmental) structure, and distribution through time such that the results of earlier events transform later events. Hollan et al. (2000) state that, to understand human cognitive potential, and to design effective human-computer interactions, it is essential to grasp the nature of these distributions of process. Note that the term DCog is semantically different from 'distributed cognition.' DCog refers to the Distributed Cognition theoretical approach, whereas 'distributed cognition' refers to cognitive processes that are distributed.

The generalisability of DCog is reflected in how it has been applied in various domains. For example, it has been used to study airline cockpits (Hutchins & Klausen, 1996), air traffic control (Halverson, 1995), call centers (Ackerman & Halverson, 1998), engineering practice (Rogers, 1993), software teams (Flor & Hutchins, 1992), control systems (Garbis & Waern, 1999), lane-changing in car driving (Haué, 2005), and representations in information visualization (Liu, Nersessian, & Stasko, 2008).

In the above studies, DCog was usefully applied to help the researchers understand the work systems being studied. However, it was applied in the form of an abstract theoretical framework. The abstractness of the framework has been its main criticism, in the sense that it is difficult to apply practically and a high level of analytical skill and familiarity with the domain are required from the researcher. This is mainly because there is not a set of pre-existing concepts that can be used to guide analysis, as discussed by Nardi (1996). To facilitate the application of DCog, Furniss & Blandford (2006) developed DiCoT during their study on emergency medical dispatch. DiCoT is a codified approach for applying DCog, which provides models and principles that can guide analysis.

2.4.2 Distributed Cognition for Teamwork (DiCoT)

DiCoT is a structured method for studying work systems and teamwork (Furniss & Blandford, 2006). It draws on the fundamental principles of DCog, described earlier, and combines them with the practical elements of contextual design (Beyer & Holtzblatt, 1998), resulting in a set of models (or themes) with associated principles from the DCog literature. The models and principles act as focal points, helping the researcher in knowing what to look for during data gathering and analysis. They also provide a way for the researcher to organise field data, into a set of interrelated models that can help understand the context of interactions and user behaviour, and that can support the derivation of insights that can inform system design. The models are of information flows, physical layouts, and artefacts.

The Physical Layout Model analyses how physical structures at different levels, for example at the desk level and at the room level, support communication among actors and facilitate access to artefacts. It also looks at how spatial arrangements support cognition, based on principles such as perception, naturalness, horizon of observation and situation awareness. The Information Flow Model describes the information flows among the actors of the system in terms of the communication channels used and key flow properties such as formal versus informal communication, information transformation, information filtering, information buffering, and decision hubs. The Artefact Model analyses how the detailed design, structure and use of artefacts aid actors in their cognitive work.

The principles can highlight potential problems, and point to possible improvements, through the implementation of the principles in system design. As an example, the principle of Naturalness in the Physical Layout Model refers to the argument of Norman (1995) that "cognition is aided when the form of the representation matches the properties of what it represents; in these cases what is experienced is closer to the actual thing, so the necessary mental transformations to make use of the representation are reduced". Rajkomar & Blandford (2012) leverage this principle in the context of infusion administration in an intensive care unit, and discuss how the work of nurses could be simplified by ordering the different infusion pumps in a pump station such that they naturally map to the order of their respective prescriptions in the computer system.

Furniss (2008) and Webb (2008) extended DiCoT with two additional models: the Social Structures Model examines how cognition is socially distributed within the system by looking at the mapping between social structures and goal structures, the sharing of work, and how robustness is achieved; and the System Evolution Model looks at the evolution of the system over time to understand why work is arranged in a particular way. Additionally, Rajkomar & Blandford (2012) developed a System Activity Model to help make sense of the different activities that happen within the system of interest and that contribute to achieving the overall system goal.Furniss & Blandford (2010) list four benefits that DiCoT can bring when moving from analysis to design: providing an understanding of the basic mechanics of the system and what makes it work; providing deeper conceptual insights into important elements of the socio-technical system; incremental design considerations arising from issues identified during analysis;

and revolutionary design considerations by using the models as tools for reflection and for playing-out the effects of potential design considerations.

DiCoT has been applied to study several work settings: emergency medical dispatch (Furniss & Blandford, 2006), mobile healthcare work (McKnight & Doherty, 2008), underground line control (Webb, 2008), software team interactions (Sharp & Robinson, 2008), infusion pump use in an oncology day care unit (Furniss, Blandford, Rajkomar, Vincent, & Mayer, 2011), and infusion pump use in an intensive care unit (Rajkomar & Blandford, 2012). The last two studies used DiCoT to study interactions with medical devices in clinical settings, and will be discussed later in section 2.4.5.

It is worth making clear the distinction between DCog and DiCoT. DCog is a theoretical framework, while DiCoT is a methodology that applies this theory in a structured way. The structure is provided mainly in terms of different models, e.g. of information flows, physical layouts, and artefacts, and the principles associated with these models. Though researchers have applied DCog in different ways, the differences lie in the *application* of the theory. The underlying theory, that cognitive processes are distributed, and that one should take a system as the unit of analysis and study how representations propagate in that system, fundamentally remains the same. The next section describes the argument for taking a DCog approach when studying healthcare work.

2.4.3 The value of a DCog approach in the healthcare context

Researchers have described the need for taking a DCog approach when studying human-computer interaction in the healthcare context. The traditional model of individual cognition does not reflect the complex nature of situated decision making that occurs among groups of individuals in healthcare work (Nemeth, Cook, O'Connor, & Klock, 2004), mixes up the processing performed by individuals with the processing performed by the larger systems in which work is carried out (Hazlehurst, Gorman, & McMullen, 2008), and has been ineffective in providing usable frameworks for improving system design at a broader level of understanding interaction within natural work settings (Patel & Kushniruk, 1998). Hazlehurst et al. (2008) state that DCog is better suited for both the study of human performance in healthcare and for the design of technologies meant to assist such work. According to Patel & Kushniruk (1998), understanding distributed cognition will become critical in the development of effective user interfaces in healthcare systems. Rajkomar & Blandford (2012) studied the use of infusion pumps in an ICU and they found significant social and physical distribution of cognition, strengthening the claim that DCog can be a framework of choice for studying healthcare work. They found that there was a high level of collaboration among nurses, that artefacts played a major role in supporting and coordinating work, and that the dynamic configuration of the physical environment influenced work. The next section summarises DCog studies in the healthcare domain and the methods used by these studies.

2.4.4 Application of DCog in the healthcare domain

DCog has been applied as an abstract theoretical framework in healthcare to study: knowledge-based controlled medical terminologies (Cimino, 1998); the spatial arrangement of patient records (Bång & Timpka, 2003); how cognitive artefacts support DCog in the operating room (Nemeth et al., 2004); the differences in interpretation of device-related critical events as a function of professional expertise (Laxmisan, Malhotra, Keselman, Johnson, & Patel, 2005); the role of cognitive artefacts in collaboration (Xiao, 2005); bottlenecks that can lead to errors in a psychiatric emergency department (Cohen, Blatter, Almeida, Shortliffe, & Patel, 2006); sign-out sheet use in a surgical intensive care unit (Nemeth, Nunnally, O'Connor, & Cook, 2006); and clinical research data collection forms (Nahm, Nguyen, Razzouk, Zhu, & Zhang, 2010). The DiCoT framework specifically has been applied in healthcare to study mobile healthcare work (McKnight & Doherty, 2008), infusion pump use in an oncology day care unit (Furniss et al., 2011), and infusion pump use in an intensive care unit (Rajkomar & Blandford, 2012).

Except for non-field-based work, which either involved theoretical analyses (Cimino, 1998; Xiao, 2005) or artefact analyses only (Nahm et al., 2010; Nemeth, Nunnally, O'Connor, & Cook, 2006), all the above studies adopted ethnographic approaches to data gathering and analysis: Bång & Timpka (2003) used participatory observations and work shadowing; Nemeth et al. (2004) conducted observations and informal interviews, recorded verbal protocols and video data, and conducted artefact analysis; Laxmisan et al. (2005) conducted semi-structured interviews designed to elicit a think-aloud protocol; Cohen et al. (2006) conducted ethnographic observations and semi-structured interviews; McKnight & Doherty (2008) conducted observations, semi-structured interviews, and artefact analysis; Rajkomar & Blandford (2012) conducted observations, informal interviews and artefact analysis; Furniss et al. (2011) used work shadowing, observations, and semi-structured interviews. The next section focuses on two of these studies, which applied DCog to study interactions with medical devices in hospital settings.

2.4.5 Application of DCog to the study of medical device use

Two of the studies mentioned above (Furniss et al., 2011; Rajkomar & Blandford, 2012) applied DCog to the study of nurses' interactions with infusion pumps. Both studies used the DiCoT framework.

Furniss et al. (2011), and Rajkomar & Blandford (2012) discovered device and interaction design deficiencies that increased the cognitive work of nurses or that could lead to safety incidents. Furniss et al. (2011) found that the infusion device did not warn the user at the point of programming when an intended therapy would outlast remaining battery charge. In one case this led to a nurse having to reprogram a new pump part way through a therapy, because the initial pump ran out of battery – reprogramming the new pump to resume the therapy was cognitively demanding as the nurse had to perform calculations with residual values. He also found that the 'Volume To Be Infused' (VTBI) parameter, which was mandatory when programming the pump, was not provided along with the prescription and nurses had to calculate it manually. He observed one particular nurse experience issues while calculating this value. Rajkomar & Blandford (2012) identified improvements in spatial arrangements that could simplify work, such as the positioning of syringe labels to facilitate perception, and the ordering of pumps in the pump rack to naturally map to the order of prescriptions in the computer system. They discovered that, while senior educator nurses possessed in-depth knowledge of pump functionality, other nurses lacked training in functionalities that could improve task efficiency, e.g. administering a bolus amount directly through a button press instead of having to program it. They also found that the pump studied required nurses to do more steps to reset the running counter of volume of drug infused compared to the predecessor pump. Another finding showed the consequences of "clumsy automation". The pump did not prompt the user to reprogram the VTBI after a nearly empty syringe was replaced, and this resulted in an incident where the pump stopped drug delivery from a new syringe earlier than intended. Fortunately, in that case the patient was not harmed. However, the incident shows how a gap in the coordination between machine and human agents can potentially cause patient harm.

These studies also unveiled nurses' interaction strategies. For example, Rajkomar (2010) found that nurses used different strategies for delivering medication through the infusion pumps, depending on how knowledgeable they were about the pump. For example, it was possible to completely bypass the VTBI step with the pump configuration used in the ICU – nurses who knew this took advantage of it and had one less step when programming the pump. Another strategy employed by nurses was putting post-it notes on pumps to indicate that the pumps 'belonged' to a particular room or theatre and keeping them in closets, although the official policy was that all pumps belonged to a common pool used across the unit. Nurses did this to safeguard against the eventuality of not finding an available pump when critically required. In these studies, DiCoT proved to be effective in generating representations of the contexts studied and in structuring and guiding the analyses that led to the above findings (Furniss et al., 2011; Rajkomar & Blandford, 2012). The next section presents some studies in the home healthcare domain that refer to DCog.

2.4.6 Application of DCog in the home healthcare domain

Two existing studies in the home healthcare domain refer to DCog. Palen & Aaløkke (2006), in the context of medication management by elderly people in the home, refer to the phenomena they observed as "a kind of distributed cognition." However, they do not mention whether they used DCog as a guiding theoretical framework in their study. Kaufman et al. (2003) mention that their usability evaluation study of a telemedicine system was informed by a DCog framework, but do not give more details on how DCog was applied in their study. Moreover, none of these studies reflects on the utility of DCog as a theoretical framework for conducting studies in such settings. The next section reviews the application of DCog to study interactions with HMDs specifically.

2.4.7 Application of DCog to the study of HMD use

The only reported study that refers to DCog in the context of studying medical device use in the home is the observational study of infusion device use in pre-term labour management by Obradovich & Woods (1996). However, Obradovich & Woods (1996) refer to it indirectly and only at the high level of describing the composition of the home care system. They do not report using DCog as an analytical tool to examine situated interactions. They describe health care as a system in which cognitive activities are distributed over multiple cooperating human and machine agents, and which is larger than the device and the patient or nurse. They state that the technology that makes the shift from hospital care to home care possible, in the context of pre-term labour, transforms the "distributed cognitive system" for providing care, by changing the roles of people. The need for effective coordination across the multiple agents increases, and the distributed system can break down in new ways. They highlight that making technology a team player requires attending to the context in which the device is to be used and designing the distributed system of human and machine agents that manages the activity in question. The next section reflects on the distribution of cognition in the home in general.

2.4.8 Distribution of cognition in the home

While no reported study was found in the literature that explicitly investigates the home using a DCog approach, previous studies give hints of cognition being distributed in the home, and also of technology participating in such distribution. According to O'Brien et al. (1999), technology use within the household is a managed activity that tends to be flexibly organized in order to enable householders to orient their activities toward those of others. This points to a social distribution of cognition, through which household members are aware of and sensitive to the activities of others. They also describe how the physical layout of the home is reconfigured based on expected activities, pointing to a physical distribution of cognition, and how technological artefacts possess a certain status, pointing to a possible artefactual distribution of cognition, as the physical layout and artefacts represent and communicate some kind of meaning to the actors of the home system. Additionally, they state that different household members undertake different activities at the same time, sometimes leading to competing demands for resources such as technological artefacts or domestic space. This implies the execution of multiple activities in parallel in the home that can influence each other, reminiscent of the concurrent activities in an intensive care unit (Rajkomar & Blandford, 2012). The findings of O'Brien et al. (1999) hint that the general, normal everyday life configuration of the home bears some resemblance to a distributed cognitive system. Looking at a home healthcare setting specifically, Obradovich & Woods (1996) describe it as a distributed cognitive system of multiple cooperating human and machine agents. This implies a social distribution of cognition, when cognition is distributed across human agents, for example between the nurse and the patient, and to an artefactual distribution of cognition, when cognition is distributed across human and machine agents, for example between the patient operator and the infusion device. The next section summarises the reflections on previous DCog studies and the implications for this research.

2.4.9 Reflections on DCog studies and implications for this research

Previous studies have shown that a DCog approach is well suited for studying healthcare systems in clinical settings with the intention of evaluating and designing technology that supports such systems. Also, the findings of previous home studies indicate that cognition is distributed in the normal home context and in the home healthcare context. Therefore, one of the aims of this research is to test the effectiveness of a DCog approach for studying situated interactions between patients and community practitioners with HMDs, in terms of understanding the context of use, of identifying device interaction design deficiencies, and of understanding coping strategies developed by users. A particular focus will be given to interaction design deficiencies and interaction strategies that are potentially associated with safety implications. As stated by Fields, Paterno, Santoro, & Tahmassebi (1999), safety is not a property of individual tasks or actions, but of the interrelationships and interconnections between parts of a system. This makes DCog an attractive candidate as a theoretical framework for studying interactions in safety-critical systems such as healthcare systems.

This third part of the literature review presented the DCog theoretical framework, reviewed previous DCog studies, and proposed it as being a useful theoretical framework for guiding situated studies of HMDs. The fourth part of the literature review presents a discussion on the implications for this research derived from the literature.

2.5 Discussion & Proposed Work

Fatal incidents have occurred with HMDs (Al-Tarawneh et al., 2004; NPSA, 2010), some of which could potentially have been prevented through better device design. Making these design improvements requires an understanding of the situated use of HMDs. Previous studies on the situated use of medical devices in clinical settings have shown that clinicians experience difficulties when interacting with the devices, suggesting that home users, who are typically less trained than clinicians, are likely to experience difficulties as well when using HMDs. Indeed, two existing studies on HMD use (Lehoux, 2004; Obradovich & Woods, 1996) have confirmed that users face difficulties when interacting with the devices, that they develop strategies to cope with these difficulties and that these difficulties or strategies can lead to safety implications. However, one of the studies focused on understanding patients' acceptance of the technologies instead of specific interaction issues, and the other involved community nurses as the main users of the technology instead of patients. This research aims to focus on understanding specific strategies and issues that patients have when interacting with HMDs.

For doing home studies, researchers have described the lack of well-developed methods, and have suggested that methods commonly used for the workplace should form a starting point (Monk, 2000; O'Brien & Rodden, 1997). Through the experience of applying these methods to home studies, they could be adapted to develop new methods for the home setting. Researchers studying the use of medical devices in clinical settings employed ethnographic observational methods, and they claim that some interaction strategies could be uncovered through observation alone. Some of these researchers recommend the adoption of an open bottom-up approach to data gathering, to avoid any biases through preconceptions, to gain a broader perspective on situated interactions and to understand the fundamental organization of work. Using ethnographic observational methods similar to those that had been used for studying medical devices in clinical settings, some researchers studied the situated use of HMDs, and were able to identify interaction design deficiencies and interaction strategies.

With regard to understanding interactions with technology more generally in the home, i.e. interactions with non-healthcare technology, O'Brien & Rodden (1997) and O'Brien et al. (1999) used an ethnographic method flexibly to study situated interactions with a set-top-box. They settled for evening sessions lasting a few hours. This was because extended fieldworker immersion in such an environment would be difficult, due to its private nature and also the practical constraints of time and resources. They argue that such an approach need not necessarily mark a departure from academic integrity, but rather makes plain one's commitment to developing an understanding of the phenomenon under investigation in its own terms, rather than imposing some form of externally-derived means of assessment. Despite compromising on the level of immersion, they gleaned useful findings, while minimizing disruption to the households and preserving the main point of ethnographic fieldwork, i.e. studying interactions within their natural, real-world settings. Therefore, this research should use an ethnographic approach flexibly, in a way that will be determined by what works best for patients and community healthcare practitioners, in terms of ethics and privacy, as well as what yields useful data.

DCog is a theoretical framework that draws on ethnographic data and that has been put forward as being particularly well suited for studying interactions with technology in healthcare socio-technical systems. From a DCog perspective, cognition in a socio-technical system is distributed through people, the physical environment, and artefacts. Technological artefacts play a key role in coordinating and supporting activity in the system. The safety of such systems has been described as a property of the interconnected components; DCog facilitates the analysis of the different cognitive components of a system, making it well suited for understanding safety implications. Although it does not report using DCog as a guiding theoretical framework, one previous study describes the home healthcare setting it studied as a distributed cognitive system consisting of the patient, the HMD, the community healthcare practitioner, and the carer. Moreover, studies of general technology use in the home have hinted that routine home life can be viewed as a system having the goal of maintaining that routine and the social organization involved, and in which cognition is distributed socially, physically and artefactually. DCog should therefore be a suitable theoretical framework for understanding situated interactions with HMDs. In particular, DiCoT, which provides a structured method to apply DCog and has been applied successfully in healthcare settings, should be able to facilitate this understanding. Additionally, because the home is a social setting, and because one previous study found that HMDs constrain the social lives of patients and carers, social factors are likely to influence the interactions of patients and carers with HMDs, and need to be taken into consideration.

Based on the literature review, the 5 research questions framed for the preliminary study are:

Empirical questions

1. *What are the interaction strategies that HMD users adopt to cope with difficulties or to optimize their interactions, and are these strategies linked to potential safety implications or interaction design issues?* Drawing on the notions of 'coping strategies' and 'tailoring strategies' discussed in the literature, I define an interaction strategy as any particular way of interacting with the technology, which can range from being at a low level and involving the immediate context of use, e.g. pressing buttons on the technology's interface in a specific order, to being at a high level and involving the broader context of use, e.g. deciding to use the technology at a specific time or performing some actions to prepare for the use of the technology. I argue that it is useful to understand interaction strategies at both ends: low-level ones can inform design to improve the direct usability of the technology, and high-level ones can inform design to improve how the technology fits into the broader life patterns of users.
2. *What are the physical and social contexts in which patients interact with HMDs, and how do these contexts influence users' interaction strategies with HMDs?*

Methodological questions

1. *What methods can be used to gather data effectively and efficiently on patients' interaction strategies with HMDs and on the context in which interactions happen?*
2. *How can DiCoT be used to understand patients' interaction strategies with HMDs and the context in which these interactions happen, in terms of a home healthcare socio-technical system?*

Theoretical question

1. *How well suited is DCog as a theoretical framework for studying patients' interaction strategies with HMDs?*

Chapter 3 will define HHT as the HMD that this research focuses on, based on available opportunities to access the field, and formulate a methodology for data gathering and analysis, based on insights from previous studies.

Chapter 3: Methodology

3.1 Introduction

This chapter presents the methodology that was formulated for this research, to study patients' interactions with HHT. It consists of three parts: 1) a first part which describes how the field was defined, which is renal patients using HH machines, how access was gained to the field, and how participants were recruited; 2) a second part which presents an initial methodology for data gathering and analysis that was formulated based on the literature review, the gist of which is the use of ethnographic methods and DiCoT; and 3) a third part which describes the methodology for data validation. The second part, the methodology for data gathering and analysis, was adapted during the preliminary study, based on challenges and opportunities found during that study. Chapter 4 will discuss these adaptations to the methodology; this chapter presents the initial methodology that was formulated based on the literature review. Also, this chapter aims to present the general methodology: the detailed methods used for the DCog analysis and CFA will be described in chapters 5 and 13 respectively. The next section states the objectives of this chapter, and then the following three sections each focus on one part of the methodology.

3.2 Objectives

The objectives of this chapter are:

1. Define "the field" for this study, i.e. the HMD(s) to be studied, how access was gained to the field, and how participants were recruited (covered in section 3.3).
2. Formulate a methodology for data gathering and analysis based on the literature review, as a solution to the second methodological research question set at the end of Chapter 2: *What methods can be used to gather data effectively and efficiently on patients' interaction strategies with HMDs and on the context in which interactions happen?* (covered in section 3.4).
3. Formulate a methodology for data validation (covered in section 3.5).

The next three sections each address one of these objectives.

3.3 Defining the field, gaining access to the field, and participant recruitment

This section first explains how the field was defined, i.e. renal patients using HHT (section 3.3.1), then summarises the ethics and approval processes undertaken for gaining access to the field (section 3.3.2), and finally describes how participants were recruited with the help of the home nurse (section 3.3.3).

3.3.1 Defining the field

This research focuses on understanding situated interactions with HMDs. After a review of the literature and consultation with healthcare practitioners, the main programmable HMDs being used in the UK were identified as being HH machines and ambulatory infusion pumps. Therefore, these two devices were shortlisted, and contact was made with healthcare practitioners to gain access to home and hospice patients and nurses who used these devices. To put a broader perspective on the research problem, initially an attempt was made to study the use of both of these devices. However, it was not possible to study the use of infusion pumps, due to organisational issues and changes. From then onwards, this research focused on the use of HH machines.

3.3.2 Gaining access to the field

The processes for getting the different permissions required to study the use of medical devices in three settings were started: the use of HH machines by renal patients of one hospital; the use of ambulatory infusion pumps by palliative care nurses of another hospital in patient's homes; and the use of ambulatory infusion pumps by nurses of a hospice. These permissions include National Health Service ethics approval and hospital-specific research & development approval. During the process to get ethics approval, the opportunity to study infusion pump use by palliative care nurses in homes phased out, seemingly due to organisational changes. It took six months to get all the permissions to start the preliminary HH study with Hospital 1 (H1) and the study of infusion pump use in the hospice. The ethics reference number for this study is 11-LO-0329. Attempts were made to gain access to home patients through non-NHS routes also, firstly by contacting some home healthcare providers and secondly by contacting some organisations that represent patients. The first route was unsuccessful, while the second route led to one participant being recruited, through an open letter that was posted on the website of the National Kidney Federation. This letter is shown in Appendix B section B.3.

3.3.3 Participant recruitment

Since this research has the goal of generating rich detailed descriptions of strategies employed by particular HMD users, and not of generalizing these strategies across patient populations, and due to the challenges of identifying suitable participants in this difficult-to-access population, availability samples of patients were used. Healthcare practitioners were consulted to inform some aspects of the study design such as likely patient population and sample sizes.

Participants were recruited for the preliminary HH study through the home nurse of H1. The home nurse informed the hospital's home patients who could be potential participants of the study, and then arranged for me to contact interested patients. I then made arrangements with the patient to visit them at home. During the first home visit to a patient, a participant information sheet was given to the patient, and the purpose of the study was explained to them, before taking their consent on a consent form. The participant information sheet and consent form were both approved by the hospital's research & development office, and different versions were produced for staff members, patient, and carers. The participant information sheet and consent form for patients are in Appendix B sections B.1 and B.2 respectively.

In parallel with the preliminary HH study, a study of nurses' use of infusion pumps in a hospice was started. However, due to uncertainties to do with the continuation of the use of the pumps and with anticipated organisational changes, that study was abandoned. From then onwards, this research focused on HH machines. In the main HH study, participants were recruited in a similar way: that is, with the help of hospital staff. The next section details the initially proposed methodology for gathering data during visits to patients and for analysing that data.

3.4 Data Gathering & Analysis

The first methodological research question formulated for the preliminary study, "*What methods can be used to gather data effectively and efficiently on patients' interaction strategies with HHT and on the context in which interactions happen?*" seeks to assess the suitability of methods for gathering data in the HH context. The second methodological research question, "*How can DiCoT be used to understand patients' interaction strategies with HMDs and the context in which these interactions happen, in terms of a home healthcare socio-technical system?"* seeks to assess the suitability of DiCoT in supporting data gathering and analysis in the HH context. It is necessary to distinguish the initial methodology that was formulated based on the literature review and that was tested in the preliminary study, from the actual methodology that was found to work in practice in the preliminary study and that was used in the main study. In this section, I present the initial methodology that was formulated based on insights from previous studies. The next chapter will discuss the results of applying this methodology in the preliminary study and the adaptations to this methodology.

Based on the literature review and the empirical research questions set for this research, the initial methodology that was formulated to study patients' interactions with HHT proposes to use ethnographic methods, with workplace methods serving as a starting point, and with the involvement of patients as co-researchers. Both top-down and bottom-up analyses were proposed: top-down to test the relevance of DCog theory in the HH setting, and bottom-up to let other non-DCog-related phenomena emerge. This initial methodology proposed to gather data on actual behaviour through multiple sources, particularly observations and interviews, and to refer to training sessions and device/system manuals to understand what constitutes prescribed behaviour. It proposed to analyse data by constructing the DiCoT models to represent the context and to analyse interaction strategies, and by performing open qualitative analyses to let other, non-DCog-related phenomena emerge. It proposed to do a preliminary study, to inform subsequent study phases based on empirical, methodological and theoretical insights gained from it. The following sections elaborate on the initial methodology.

3.4.1 The general approach: ethnographic methods

As discussed in the literature review in Chapter 2, previous DCog studies and other studies of situated use employed ethnographic methods, and one previous study of medical device use in a clinical setting claims that situated strategies and their effects cannot be predicted from device characteristics alone, stressing the need for an observational methodology (Cook & Woods, 1996). Therefore, the initial methodology proposed to employ ethnographic methods in this research to gather detailed data about how HHT users interact with the technology in practice, and on the broader context in which these interactions happen.

3.4.2 Coping with a lack of well-developed methods for the home context: workplace methods serving as a starting point

The reviewed literature stresses that there is a lack of well-developed methods for doing home studies, and recommends that methods used for the workplace should serve as a starting point. Following this recommendation, the initial methodology proposed to use methods that have been used to study medical devices in clinical settings as a starting point to study medical devices in the home setting, and to adapt the methods through the experience of applying them and through feedback from participants and home healthcare practitioners. Also, some of the limitations of applying methods such as observations and interviews in the home that are described in the literature were foreseen based on the depiction of the home as a place where interactions with technology can be leisure-driven, without participants having clear motivations for engaging in them, contrasted with interactions in clearly-defined workplace tasks. Arguably, the home healthcare setting is yet another kind of context – perhaps one that is somewhere between the normal home context and the workplace context, assuming interactions with HHT can be treated as a kind of 'serious task.' Therefore, current workplace (clinical setting) observation and interview methods should not be easily discounted for the home healthcare setting, and the initial methodology proposed these as a starting point.

3.4.3 A potential solution to the problem of methods: recruiting patients as co-researchers

Blandford et al. (2009) suggest an approach of partnering with patients and carers in critiquing the design of the technology they use, involving the collection of data about minor incidents through diaries, interviews and video capture. The initial methodology proposed to experiment with this approach, by inviting participants to keep diaries of minor incidents, either through loaned handheld video equipment or pen and paper.

3.4.4 A mixture of top-down and bottom-up approaches: testing DCog theory while being open to other phenomena

Like previous studies of medical device use in clinical settings, the initial methodology proposed to collect data on the broader context in which interactions with HHT happen. One previous study recommends an open bottom-up approach to data gathering, to allow phenomena to emerge (Randell, 2003). The initial methodology proposed to gather data through a mixture of top-down and bottom-up approaches, since one of the objectives of the research is to explore the question of whether DCog is a useful theoretical framework for studying the home healthcare socio-technical system. Therefore, some parts of the data gathering were intended to focus on collecting data for constructing the DiCoT models (top-down), and some parts were intended to focus on collecting data on the broader context in an open manner, to let other phenomena that influence patients' interactions with HHT emerge (bottom-up).

3.4.5 A combination of several sources of data: observations, interviews, video diaries, artefact analysis, incident data, and trainings & manuals

Previous studies in the reviewed literature combined several sources of data, and this was the aim of the initial methodology as well, through six sources: 1) direct observations of patients' and carers' interactions with HHT; 2) audio-recorded semi-structured interviews with patients, carers and practitioners; 3) working with patients as co-researchers through video or paper diaries kept by patients; 4) analyses of device behaviour through bench tests; 5) institutional data on actual incidents; and 6) attending training sessions and consulting system/device manuals to understand prescribed behaviour. Investigations through the different sources were intended to be iterative and intermixed, with one type of investigation informing another.

3.4.6 Observations

Based on previous studies of medical device use in clinical settings, the initial methodology proposed to employ unobtrusive observations, using observation sheets and other aids such as process flow diagrams to record interactions between users and HHT, and the broader context of interactions. It proposed to use observations both to understand the context in which interactions with HHT happen and to understand the details of actual interaction strategies. One previous study found variations in practitioners' workloads at different times of the day, and argues that it is in periods of high workload that "clumsy automation" features can have the most negative impact (Cook & Woods, 1996). Therefore, the initial methodology proposed to conduct observations at different times of the day, in case there are related variations in the workload of community healthcare practitioners or in patients' interaction patterns.

3.4.7 Interviews

Similar to previous studies in the reviewed literature, the initial methodology proposed to conduct semi-structured as well as informal interviews to: understand the domain, understand particular events in the setting, get clarifications on actions performed by observed participants to understand their interaction strategies, and to elicit critical incidents (Flanagan, 1954) that patients had had with HHT. The initial methodology proposed to audio-record semi-structured interviews, and to conduct informal interviews during breaks or quiet periods where applicable.

3.4.8 Understanding prescribed behaviour: trainings and manuals

The methods described so far mostly focus on understanding actual behaviour. To see how actual behaviour deviated from prescribed behaviour in previous studies, researchers attended training sessions and referred to device/system manuals, to understand what constituted prescribed behaviour. Similarly, to help ascertain the differences between prescribed ways of using devices and actual user strategies, the initial methodology proposed the attendance of training sessions where possible, and the consultation of device/system manuals.

3.4.9 Data analysis: constructing the DiCoT models (top-down) and open qualitative analysis (bottom-up)

The initial methodology proposed a top-down analysis that involves using DiCoT to structure parts of the data gathering, and analysing data to build the DiCoT models to represent the context of HH. Appendix B section B.4 shows how it proposed to gather data in a top-down fashion for building the DiCoT models, in terms of the data gathering techniques to be used and example interview questions.

Additionally, the initial methodology proposed a bottom-up analysis that involves doing an open qualitative analysis of data that does not fit into the above DCog analyses, to let other phenomena that influence patients' interactions with HHT emerge.

3.4.10 A phased approach: to understand the domain and to adapt methods to what works best for participants

Like the DCog study of Bång & Timpka (2003), the initial methodology proposed that the initial phase of the data gathering should focus on understanding the domain, and that subsequent phases should focus on the DCog analysis. As discussed in Chapter 2, data gathering methods need to be used in a flexible way, considering what works best for participants. Also, the literature stresses the ethics and privacy issues involved with the study of home healthcare technologies specifically. In consideration of these, the initial methodology was tested in the preliminary study in an exploratory way, to determine what works best for patients, carers and practitioners, and what yields data effectively and efficiently. Based on the findings of the preliminary study, in the light of opportunities and challenges encountered, the initial methodology was adapted for the main study. Also, empirical and theoretical insights gained from the preliminary study informed the DCog analysis in the main study. The next section describes the methodology for data validation in this research.

3.5 Data Validation

Data validation is achieved in three ways in this research: the groundedness of the analysis of the data, triangulation, and inspection. Member checking was not used throughout this research, because, as discussed by Barbour (2001), it was deemed to be "more trouble than it is worth," especially considering the demands it would pose on patients' limited available time.

3.5.1 Groundedness of the analysis in the data

The analyses conducted in this research are based directly on data gathered from patients on their interaction strategies and issues. During analysis, data was kept as-is, except for paraphrasing of interview data in some cases, to summarise phenomena that were described in lengthy text. Such groundedness of the analysis in the data provides for data validation.

3.5.2 Triangulation

Data was gathered through a number of sources, the main ones being direct observations, interviews and diaries. Investigations through the different sources were iterative and intermixed, with one type of investigation informing another. Such triangulation of data helps ensure the validity of data.

3.5.3 Inspection

Samples of the data gathered in this research are available in the appendices of this thesis, and the process through which data has been analysed is given in each relevant chapter, to allow third parties to inspect the data and understand how insights were derived from that data.

3.6 Summary of this chapter

This chapter described the general methodology of this research. The first part explained how the field of study was defined, how access to the field was gained, and how participants were recruited. The second part proposed methods for data gathering and analysis, based on the literature review, which then got adapted during the preliminary study, presented in the next chapter. The third part described data validation for this research.

Chapter 4: Preliminary Study

4.1 Introduction

This chapter presents the results of the preliminary study and the implications for this research. The goal of this study was to seek preliminary answers to the research questions formulated at the end of the literature review in Chapter 2. This includes testing the initial methodology formulated in Chapter 3, to see what works and what does not work in practice in the particular HH setting being studied. Section 4.2 describes the objectives of this chapter, based on these research questions, in three threads: empirical, methodological and theoretical. Section 4.3 describes the methods used in the preliminary study. Then, sections 4.4 to 4.6 focus on the empirical findings, the methodological findings, and the theoretical findings of the preliminary study, respectively.

4.2 Objectives

The overall objective of the preliminary study was to get empirical, methodological, and theoretical insights on the study of patients' interactions with HHT, to inform the rest of the research and identify issues that need to be addressed in the main study.

4.2.1 Empirical objectives

The preliminary study sought to preliminarily explore the two empirical research questions formulated after the literature review:

1. *What are the interaction strategies that HHT users adopt to cope with difficulties or to optimize their interactions, and are these strategies linked to potential safety implications or interaction design issues?* (covered in section 4.4.1)
2. *What are the physical and social contexts in which patients interact with HHT, and how do these contexts influence users' interaction strategies with HHT?* (covered in section 4.4.2)

4.2.2 Methodological objectives

The preliminary study sought to test out the methodology formulated in Chapter 3 and identify any adaptations that need to be made to it, effectively answering the two methodological research questions that were formulated after the literature review:

1. *What methods can be used to gather data effectively and efficiently on patients' interaction strategies with HHT and on the context in which interactions happen?* (covered in section 4.5.1)
2. *How can DiCoT be used to understand patients' interaction strategies with HHT and the context in which these interactions happen, in terms of a home healthcare socio-technical system?* (covered in section 4.5.2)

The initial methodology that was formulated in Chapter 3 essentially consists of using ethnographic methods (observations, interviews, and video/paper diaries) and DiCoT to gather and analyse data on patients' interactions with HHT.

4.2.3 Theoretical objective

The preliminary study sought to explore the theoretical research question formulated after the literature review: *How well suited is DCog as a theoretical framework for studying patients' interactions with HHT?* (covered in section 4.6.1).

4.3 Methods

The preliminary study was conducted with 5 patients, 4 from Hospital 1 (H1) and 1 from Hospital 2 (H2), and with the renal home nurse of H1.

4.3.1 Data gathering

The home nurse was interviewed and the 5 patients were visited in their homes. The participants, referred to by fictitious names, are: Adam, self-caring patient who lives with his wife and his child; Carl, carer of his dad Bob; Cindy, carer of her husband Eric; Fiona, self-caring patient who lives on her own; and Alice, self-caring patient who lives with her partner and her daughter. These patients use three different HH machines. During a visit to a patient, the patient and their carer were observed during part of the dialysis treatment, and then they were interviewed. Typically, they were observed for about 30 minutes during the treatment preparation phase and then interviewed for about 45 minutes during the treatment, or they were observed for about 30 minutes during the treatment termination phase and then interviewed for about 45 minutes after the treatment. The interview was semi-structured and consisted of questions that sought to elicit data to construct the DiCoT models (for a top-down analysis), and other more general questions that sought to understand the patient's experience of using the technology and how the technology fits into their daily life (for a bottom-up analysis). A home visit guide was used to structure the visit to a patient, including interview questions. This guide is in Appendix C section C.1. The physical environment where the patient dialyses was observed and photographs of it were taken, to help understand the physical context in which the patient dialyses. Photographs of artefacts, e.g. the patient's dialysis chart and other information artefacts located at the dialysis site, were also taken, to help understand patients' interaction strategies. The patient or carer was invited to keep a diary of minor incidents, either through a loaned handheld video recorder or pen and paper. The data gathering methods of this study are reviewed in more detail in section 4.5.1.

4.3.2 Data analysis

Interviews were transcribed and observation notes were typed up. An example of a transcribed interview (for Carl) and an example of observation notes (for Cindy & Eric) are in appendix C section C.2. A preliminary DiCoT analysis was completed (top-down), to see how the gathered data could be analysed using DiCoT, both to represent the context and to understand patients' interaction strategies. Secondly, an open qualitative analysis of the data was done (bottom-up), to understand how the context in which interactions happened influenced interaction strategies in a more general sense, and to let other phenomena not captured by DCog emerge. Both of these analyses were captured in an analysis document. Extracts from interview transcripts and observation notes were copied into relevant sections of this document. Data that could be analysed through one of the DiCoT models were copied into a section of the analysis document corresponding to that model, which could be 'Information Flow', 'Physical Layout', 'Social Structures' or 'Artefacts'. Appendix C section C.3 shows samples of data analysis in the 'Physical Layout' section of the analysis document. Data that did not fit into the existing DiCoT models were copied into one of four general sections of the analysis document, namely 'Impact of technology on life', 'Interaction strategies and experiences', 'Knowledge and troubleshooting' and 'Activities during dialysis'. Appendix C section C.4 shows samples of data analysis in the 'Interaction strategies and experiences' section of the analysis document. The data analysis methods of this study are reviewed in more detail in section 4.5.2.

4.4 Empirical findings of the preliminary study

This section presents the findings of the preliminary study in terms of the two empirical questions formulated after the literature review. The examples of interaction strategies discussed in the rest of this chapter are drawn from the analysis document previously mentioned in section 4.3.2. In the home haemodialysis settings reported in this thesis, a patient or carer who is eligible for doing the treatment is trained in a dialysis unit by nurses. When they are ready to do the treatment independently, the machine is installed in their homes by specialist technicians, and they commence treatment at home. They receive on-going support from nurses for treatment-related issues and from technicians for technology-related issues. This forms a distributed cognitive system consisting of the patient, the carer/helper, the nurse, the nephrologist, the technician, HHT, and other artefacts such as the patient's dialysis chart.

4.4.1 Empirical question 1: What are the interaction strategies that HHT users adopt to cope with difficulties or to optimize their interactions, and are these strategies linked to potential safety implications or interaction design issues?

It was found in the preliminary study that renal patients employ optimizing and coping strategies when interacting with HHT, and some of these strategies are complex in the sense that they involve several contextual factors. These strategies point to interaction design issues, and some are linked to potential safety implications.

Some interaction strategies employed by patients and carers to cope with difficulties or to optimise interactions were found in the preliminary study. As an example of a strategy employed to cope with a difficulty, Adam, who, on some occasions used to forget to inject an anticoagulant into the dialysis circuit before starting dialysis, lays out all items on a table before he starts to prepare for dialysis. Then, one by one, he removes the items from the table, and at the end of preparation, if he has performed all required steps, there should be nothing left on the table. This strategy points to a safety implication: if the anticoagulant is not injected, blood will start clotting in the extracorporeal circuit, and the patient may suffer from complications linked to haemolysis. As an example of a strategy employed to optimise interactions, Alice installed her dialysis machine on her verandah and she dialyses there, as it is a nicer environment than indoors (optimising on comfort), even though she has to heat the verandah in winter to keep the machine functioning properly. Therefore, patients do adopt interaction strategies, both coping and optimising ones, when interacting with HHT. Furthermore, some complex interaction strategies were found in the preliminary study, which are based on several contextual factors. As an example, Carl, who operates the dialysis machine for his dad, gets his mum to start the disinfection process of the machine while he is on his way to his parent's home. To enable her to do the disinfection, he put stickers on the machine's interface to indicate which buttons she needs to press. There are several contextual factors at play in this particular interaction strategy, and section 4.5.2.6 will revisit this strategy.

These strategies point to interaction design issues which, if fixed, could lead to a smoother experience for patients, who are already stressed and fatigued due to their illness. Also, though patients and carers mentioned they had no problems interacting with the technology during 'ordinary use', they struggle during situations of 'extraordinary use', when e.g. they encounter new alarms and messages from the machine. Therefore, patients' interaction strategies with HHT can point to interaction design issues that can inform more usable designs of HHT.

4.4.2 Empirical question 2: What are the physical and social contexts in which patients interact with HHT, and how do these contexts influence users' interaction strategies with HHT?

It was found in the preliminary study that different patients interact with HHT in different physical and social contexts, and these contexts influence their interaction strategies. Furthermore, the broader context influences interaction strategies.

The physical context in which patients interact with HHT can be the patient's bedroom (Adam, Eric and Fiona), a special purpose room (Bob), or their verandah (Alice). This physical context can influence a patient's interaction with HHT. For example, the physical layout in the home, which is different to the physical layout in the dialysis unit, can create situations that lead to new alarms that a patient did not encounter while training in the unit. Adam reported that, on one occasion, his arterial line, which was taut due to the machine being quite far from him, displaced the concentrate line from its canister, as the two lines were crossing each other. This resulted in an alarm he had not dealt with before; according to him, in the unit the layout is such that the two lines would not cross. After struggling to find the cause of the alarm for a while, he eventually noticed that the concentrate line was dislodged, and realised that that was probably the cause of the alarm.

The social context in which patients interact with HHT can vary from them being completely alone to them living with their family. This social context can influence a patient's interaction strategy. For example, Fiona, who lives on her own makes sure she keeps painkillers next to her on the bed before she starts dialysis, as there will be no one to get some for her later on if she gets bad headaches. On the other hand, Adam, who lives with his wife, gets his wife to start the auto-disinfection process on the machine sometimes, e.g. while he is driving back home, to save time. The broader context can also influence a patient's interaction strategy. For example, Adam ensures that he finishes his dialysis and switches off the machine at a certain time in the evening, so that the machine's running noise does not disturb his young sleeping son. Therefore, the contexts in which patients interact with HHT do influence their interaction strategies, and should be considered in the analysis.

4.5 Methodological findings of the preliminary study

This section presents the findings of the preliminary study in terms of the two methodological questions formulated after the literature review.

4.5.1 Methodological question 1: What methods can be used to gather data effectively and efficiently on patients' interaction strategies with HHT and on the context in which interactions happen?

The methodology formulated in Chapter 3 proposed to gather data through six sources: 1) direct observations of patients' and carers' interactions with HHT; 2) audio-recorded interviews with patients, carers and practitioners; 3) working with patients as co-researchers through video or paper diaries kept by patients; 4) analyses of device behaviour through bench tests; and 5) institutional data on actual incidents; 6) attending training sessions and consulting system/device manuals.

It was found in the preliminary study that: 1) observations could be done mostly in an opportunistic and unstructured way; 2) interviews were effective with the use of the critical incident technique; 3) patients did not have the time, energy or enthusiasm to keep video/paper diaries, due to their preoccupation with their illness; 4) it was not possible to get access to the HH machines for doing bench tests; 5) it was not possible to access institutional data on incidents, as there were no computerised records of support calls received by technicians; and 6) there was no timely opportunity to attend training sessions, and the fact that different participants used different machines having different operating procedures, and had received different training from different practitioners, made the consultation of manuals impractical. The next six sections each elaborate on one of these six sources of data.

4.5.1.1 Observations: opportunistic and unstructured

During the preliminary study, observations tended to be unpredictable in duration and frequency, and it was not really possible to conduct observations in a structured way, e.g. using process diagrams or observations sheets. This was because participants had different preferences for when they were willing to be observed, which could be at different stages of dialysis preparation and treatment. Also, when I visited some participants, they had already performed some steps of the preparation (unlike what we had agreed on the phone). It was therefore not practically possible to observe them throughout the whole treatment from beginning to end; rather, observations of actual interactions were more opportunistic in nature. This means that observations are not well suited to be a staple source of data on patients' interactions with HHT. However, observing and taking pictures of the physical context in which patients dialyse worked well, and helped to understand that physical context.

4.5.1.2 Interviews: effective with the use of the critical incident technique

Interviews with the home nurse and with patients worked well, and were the most substantial source of data, especially with the use of the critical incident technique. There are some challenges when interviewing patients on their experiences with technology. The first challenge is that, in such a setting, where the technology is life-sustaining, there is naturally a very high acceptance of the technology, regardless of any design flaws it may have: the interaction difficulties a patient or carer might face while using the technology are peripheral from their perspective, in fact so peripheral that they might not mention them at all. There is also an ethical question of how far should the researcher probe in the critique of the technology, such that the patient does not lose confidence in the technology, as they depend on it for staying alive. The second challenge is that some patients and carers are grateful to have the technology at all in their homes, which makes their lives much easier than having to go to the dialysis unit. Consequently, they may have an inclination to 'protect' the system that makes this possible for them; they wouldn't want either other people in the system or the technology to be seen in a bad light. This can make involving them in critiquing the technology even more problematic. Thomson, Martin & Sharples (2013) report a similar "gratitude and satisfaction bias" when interviewing older people on the use of medical devices in the home. Thirdly, for patients and carers, there is not necessarily a distinction in what constitutes a design flaw, versus what constitutes a lack of competency from the user. On some occasions, patients seemed to want to ensure that they were perceived as being capable of fully handling the machine. This might be either a matter of pride or a matter of ensuring that they were perceived as possessing the required competencies for conducting their treatment independently; after all, they had been formally assessed on this before being allowed to start HH. This means that they may be guarded in critiquing the technology, as any critique could be perceived as a lack of competency on their part. Finally, it may be tricky for a patient or carer, who may not be acquainted with HCI or the concept of usability, to understand the motivation behind the study.

The critical incident technique helps overcome these challenges, firstly by giving a clear focus to the interview, which participants can understand, i.e. incidents they have had with the technology, and secondly, by making clear actual facts (incidents) from participants' more general opinions and impressions, which may be biased due to some of the reasons described above. Therefore, interviews of patients focusing on incidents they have had while using the technology can be a staple source of data on patients' interaction strategies and issues.

4.5.1.3 Working with patients as co-researchers through video/paper diaries: patients not having the time, energy or enthusiasm due to their preoccupation with their illness

The attempt to recruit patients as co-researchers and get them to keep video/paper diaries did not work in the preliminary study. Though three participants agreed to keep handheld video recorders to record minor incidents with the technology, after a period of three months, they had not recorded anything. One participant who self-cares mentioned that, when an incident happened, it was not practical for him to hold the recorder in one hand and try to fix the problem with the other hand (they were provided with small tripods, but this still requires them to carefully adjust the position and angle of the camera). Another participant who is a carer mentioned that when an incident happens, his reflex was to fix the problem as soon as possible, and not to record it. The two other participants, who did not keep video recorders, were not willing to keep pen and paper diaries instead. One participant mentioned that she had already been keeping notes of alarm codes and solutions for these given by the technician in her dialysis chart, and offered that I could take pictures of those instead of her keeping a diary. The other participant faxes a weekly summary of her dialysis and any incidents to her hospital, and offered to email those to me instead of her keeping a diary (but she did not do so eventually). Essentially, renal patients are overworked, stressed, and fatigued due to their illness and its invasive treatment, and therefore they may not have the time, energy or enthusiasm to engage with the research as co-researchers. This means that video/paper diaries are not well suited to be a staple source of data on patients' interaction strategies with the technology.

4.5.1.4 Analyses of device behaviour through bench tests: no access to devices

It was not possible to get access to the HH machines to do bench tests, and additionally, since the participants used three different machines, it would have been even more impractical to do so.

4.5.1.5 Institutional data on actual incidents: no computerised data available

It was not possible to get access to institutional data on actual incidents. When technicians get calls from patients, they record the call on a form, which does not get computerised. For me to get access to these forms, staff members would have to manually photocopy the forms, anonymise them, and send them to me, making this an impractical source of data.

4.5.1.6 Attending training sessions and consulting system/device manuals: no opportunities for attending sessions and consultation of manuals not practical

It was not possible to attend a training session, and the consultation of system/device manuals was found to be impractical. The patients who were being trained at the satellite unit during the preliminary study had already been trained on doing their dialysis treatment themselves long before, and were simply doing their treatment on a different machine model that would be installed in their home eventually, under the supervision of unit nurses. Therefore, there was no training session as such being held in the unit. Also, it was not practically possible for me to observe patients' interactions with machines in the satellite unit, as there was no space or place for me to position myself in the room, which was very cramped and busy. The fact that the participants of the preliminary study used three different machines, having different operating procedures, and had been trained by different nurses and had learnt different procedures for using their machine, coupled with the fact that dialysis treatment is complex, made the consultation of device manuals impractical. Therefore, the possibility to compare actual behaviour with prescribed behaviour by referring to the content of training sessions and device manuals is very limited in practice. The most substantial source of data for understanding prescribed behaviour came from the interview with the home nurse.

To summarise, the sources of data that worked well in the preliminary study are: 1) semi-structured interviews that focus on critical incidents; 2) observations and pictures of the physical contexts in which patients dialyse; 3) opportunistic, unstructured observations; and 4) pictures of records in patients' dialysis charts and diaries. Therefore, data was gathered in the main study through these sources.

4.5.2 Methodological question 2: How can DiCoT be used to understand patients' interaction strategies with HHT and the context in which these interactions happen, in terms of a home healthcare socio-technical system?

The findings of the preliminary study show that a methodology of using DiCoT to analyse patients' interaction strategies with HHT and the context in which these interactions happen can work in practice. Firstly, to match the data gathering technique that works best, i.e. interviews focusing on critical incidents, the DiCoT analysis can focus on analysing these incidents to understand patients' interaction strategies. Secondly, the descriptive power of the DiCoT models can help understand the context in which patients interact with HHT and how activity happens in that context. Thirdly, the different principles associated with the DiCoT models can serve as theoretical lenses, helping to identify interaction strategies that are based on different forms of distributed cognition. Sections 4.5.2.1 to 4.5.2.3 elaborate on these opportunities of applying DiCoT.

However, three analytical problems were identified. Two of these problems can be solved by adapting the DiCoT analysis. These two problems are: firstly, how to scope DiCoT analysis in the HH context, which does not consist of a clearly bounded socio-technical system; and secondly, how to account for the fact that there is not just one unique system, but several instances of that system (one for each participant), when doing the DiCoT analysis. Sections 4.5.2.4 and 4.5.2.5 elaborate on these two problems and the proposed adaptations to the DiCoT analysis.

The analytical problem that cannot be solved by adapting the DiCoT analysis is how to analyse complex interaction strategies, which are related to several contextual factors, in a coherent way. This limitation is addressed through the development of CFA, an analytical framework of contextual factors. Section 4.5.2.6 illustrates this analytical problem, and then section 4.5.2.7 presents an initial derivation of CFA.

4.5.2.1 Adapting the DiCoT analysis to data gathering possibilities: focusing on incidents elicited during interviews to understand interaction strategies

As described earlier, semi-structured interviews focusing on incidents were the main source of data in the preliminary study. Discussing with patients about incidents they had had helped to identify their interaction strategies. For example, Adam mentioned an incident he had had before, when he used to forget to inject the anticoagulant, in which blood clotted in the circuit. This incident pointed to his current interaction strategy of laying out everything on the table. He then mentioned another incident in which a random item on the table occluded the anticoagulant and he forgot to inject it. This incident pointed to a vulnerability in his current interaction strategy.

4.5.2.2 Modelling the context: descriptive power of the DiCoT models

Constructing the DiCoT models of information flows, physical layouts, social structures and artefacts gives a rich understanding of the social and physical contexts in which patients interact with HHT and a rich description of how activity happens. These models will be presented in subsequent chapters.

4.5.2.3 Analysing cognitive interaction strategies: power of the DiCoT principles

The DiCoT principles serve as lenses to analyse interaction strategies that are cognitive in nature. E.g. the physical layout model has a principle stipulating that actors may make use of space to support cognition through spatial arrangements. This principle gives analytical power to understand Adam's interaction strategy of laying out all items on a table to remember to inject the anticoagulant.

4.5.2.4 Addressing the complexity of the context in which interactions happen: not one clearly bounded socio-technical system but several systems influencing interaction strategies

In previous DiCoT studies of control room settings, the context was clearly structured, and consisted of actors with clearly defined roles and responsibilities, working on clearly defined tasks, within a clearly bounded socio-technical system. In one DiCoT study of an ICU setting (Rajkomar & Blandford, 2012), the context was found to be more complex, in the sense that there was less structure and more influences on activity. In the preliminary study, it was found that the context of HH is even less structured and there are even more influences on activity. In the ICU study, there were many activities happening within one socio-technical system. In the context of HH, there is not a clearly defined and bounded socio-technical system – instead, there are several systems influencing how patients interact with HHT. Therefore, to capture and understand the context which influences patients' interaction strategies, the context needs to be represented in terms of several systems. The boundaries between systems are defined by the different purposes for which the systems exist. For instance, the Home Haemodialysis System exists specifically to provide renal replacement therapy to a patient at home, while the Home System exists to provide a place of residence to a person or family.

The following are three examples found during the preliminary study of how three systems from the broader context of use (Home System, Dialysis Unit System and Society System) influence patients' interaction strategies. Adam ensures that he finishes his dialysis and switches off the machine at a certain time in the evening, so that the machine's running noise does not disturb his young sleeping son, who is part of the broader Home System. This shows how the broader Home System can influence a patient's interaction strategy. Alice gets contacted by other patients who want to double check something they are unsure of regarding the use of the machine, but prefer contacting that patient instead of the home nurse, as they do not want the nurse to think that they were not paying attention to her instructions. Therefore, a patient may influence other patients' interactions. This is an example of the broader Society System influencing how patients interact with HHT. Some participants reported that the different nurses they observed in the dialysis unit took different steps while interacting with haemodialysis machines. While most participants decided to strictly stick to the steps learnt from a particular nurse, as a safety precaution, some participants incorporate what they observed from other nurses in their own interactions with the machine. This shows that, besides the learning that happens through the home nurse, the interaction strategies of patients and carers can also be influenced by other nurses from the Dialysis Unit System.

4.5.2.5 Accommodating the fact that there is one instance of the Home Haemodialysis System for each patient: structuring the analysis in terms of DiCoT principles

In previous DiCoT studies, there was only one instance of the socio-technical system being studied, and therefore only one physical context and only one social context. This was reflected in the way the analyses were reported. For each model, one overall analysis was reported, in terms of four levels of description. In the case of this study, there is not just one unique instance of the HH socio-technical system, but several instances, one for each participant. Each participant has their own physical context and social context in which they interact with HHT. Therefore, the analysis for a particular DiCoT model should be structured in terms of the principles associated with that model, and for each principle, phenomena for different participants could be reported. Essentially, since it is not possible to give a single generalised account across all participants for each DiCoT model, the principles associated with the models should serve as common threads to report phenomena for different participants, thus avoiding an implicit generalisation of the context across all participants.

4.5.2.6 Analysing interaction strategies related to several Contextual Factors: limitation of DiCoT and development of CFA

Some interaction strategies identified during the preliminary study are related to several Contextual Factors (CFs), which could involve both cognitive factors and non-cognitive factors. DiCoT cannot be used to study such strategies as a coherent whole, as it does not provide an analytical structure that considers several aspects of a strategy together. To illustrate this, an example of an interaction strategy having two parts, which span across the broader context, is presented. Carl, who does the dialysis for his dad, has to drive to his dad's place in the morning. To save time, he gets his mum, who is elderly and not trained to care for the patient or use the machine, to start the disinfection phase of the machine while he is on his way. This phase takes about fifty minutes to complete. To enable his mum to do the disinfection, he stuck four red dots on the touchscreen of the machine, next to the buttons that need to be pressed to do the disinfection. In this case, the mum is not directly part of the Home Haemodialysis System, but part of the broader Home System in which the Home Haemodialysis System is embedded. This interaction strategy involves the immediate context of technology use, in the sense that Carl modified it by adding the stickers to the touchscreen of the machine, and the broader Home System, since the carer's mum belongs to it.

If we analyse the above interaction strategy from a DiCoT perspective, the insights are: firstly, that Carl shares the goal of doing the disinfection with his mum (an example of social distribution of cognition, derived from the Social Structures Model of DiCoT); and secondly, that the mum, who has no training in using the technology, relies on artefacts created by Carl, i.e. the stickers on the screen, to be able to do the disinfection (an example of artefactual distribution of cognition, derived from the Artefact Model). While these are interesting insights, a DiCoT analysis is limited, because it provides enough structure for analysing parts of the strategy, but in a disjoint manner – it does not facilitate the analysis of the strategy as a coherent whole. I argue that it is essential to analyse a complex interaction strategy as a coherent whole, by considering the different parts of the strategy and their related CFs together, for two main reasons: firstly, since context varies for every participant, an interaction strategy cannot be analysed independently of that particular participant's context – the CFs that are related to this strategy need to be considered in this analysis; and secondly, this gives a richer understanding of the interaction strategy, in a way that facilitates the derivation of implications for design. The DiCoT analysis cannot readily achieve this, because it does not directly take into account the CFs that motivate the different parts of a complex interaction strategy, which, if considered, would link the different parts of the strategy together. This insight constitutes the foundation of CFA, which aims to overcome this limitation of the DiCoT analysis, by explicitly considering the CFs that motivate an interaction strategy. No existing analytical tool was found in the literature that provided a representational structure for reasoning about the different factors associated with a strategy in an integrated manner. Another more general limitation of DiCoT is that it does not provide an explicit structure to move from analysis to design implications. CFA attempts to overcome that limitation as well. The derivation of CFA is explained in the next section.

4.5.2.7 Derivation of CFA: Coping/Optimising Interaction Strategies, Contextual Factors, and Design Implications

Coping and optimizing strategies. The examples of interaction strategies found in the preliminary study, e.g. Carl getting his mum to do the disinfection and Alice dialyzing in her verandah, involve coping and optimizing strategies. A coping strategy is one in which an actor normally has trouble executing a function, and adopts a certain strategy that enables the execution. An optimizing strategy is one in which an actor is already able to execute a function in the system, but adopts a certain strategy to optimize on some benefit. In the first example, the optimizing strategy is getting the mum to do the disinfection, the motivation being to save time. The coping strategy is the mum relying on the stickers to press the buttons required for the disinfection. In the second example, the optimizing strategy is doing the dialysis in the verandah, the motivation being that it is a more relaxing environment (optimizing on comfort). The coping strategy is using a heater to keep the machine heated in winter.

Contextual factors enabling/causing optimizing/coping strategies and mediating cross-system strategies. We can view the context itself as explicitly shaping and mediating the above strategies. The optimizing strategies discussed above are afforded by CFs, while the coping strategies are caused by CFs. In the first example, the optimizing strategy of getting someone else to do the disinfection is possible because of the (social) CF that another family member is available in the household to do the disinfection. The coping strategy of relying on the stickers for doing the disinfection is caused by the CF that the mum is elderly, illiterate and not trained to use the machine. There is also a motivational CF which is the raison d'être of the whole strategy, namely that the carer wants to save time. Considering the CFs underpinning observed strategies in this way has two benefits: firstly, by explicitly considering the motivational CFs in the analysis, a strategy that consist of several parts, possibly spanning across the broader context, can be analysed as a coherent whole, solving the first limitation of the DiCoT analysis mentioned in the previous section – the different parts of the strategy are chained together via the CFs; secondly, by unpacking the CFs related to a particular strategy, a rich picture of the context and of use in that context can be obtained, highlighting problems that users face and potential interventions regarding technology design. Essentially, the power of CFA lies in the fact that it explicitly considers context as mediating and shaping interaction strategies.

Moving from observed strategies to CFs to design implications. After the CFs related to a particular strategy have been unpacked, reflections can be made on design implications. Design implications can be of many types, for example we may identify a new requirement for technology design, or we may find that a certain element of the design is very important in supporting current practice and should be retained in future designs, or we may identify a need for improving the training. By reflecting on design implications, based on observed strategies and their related CFs, we have a structured way of moving from analysis to design, solving the second limitation of the DiCoT analysis mentioned before.

4.6 Theoretical findings of the preliminary study

This section presents the findings of the preliminary study in terms of the theoretical question formulated after the literature review.

4.6.1 Theoretical question: How well suited is DCog as a theoretical framework for studying patients' interaction strategies with HHT?

In the preliminary study, examples of distributed cognition were found in the HH setting, and the existing DiCoT principles can be readily used to analyse such phenomena. This suggests that DCog is a suitable theoretical framework for understanding the context in which patients interact with HHT and their interaction strategies and issues, through DiCoT. However, through the bottom-up analysis conducted in the preliminary study, two gaps were identified in the existing principles. Firstly, some strategies involve a kind of temporal distribution of cognition not currently addressed in the DCog literature. Secondly, some strategies arise because of a patient's individual knowledge or because of their values and preferences; since DCog has a systemic focus, it does not provide suitable lenses for understanding such strategies.

In the preliminary study, examples of interaction strategies involving cognition distributed through the physical environment, through social structures, through artefacts, and through time were found. An example of physical distribution is the way Alice organises the storage of her medical supplies, such that specific types of supplies are kept in specific drawers. An example of social distribution is Adam getting his wife to start the disinfection of the machine, effectively sharing the goal of that task with her. An example of artefactual distribution is Cindy recording solutions for alarms, which she got from the technician, in Eric's dialysis chart, for future reference. The top part of Figure 4.1 below shows the recording of a solution in the dialysis chart. The solution is turning the Reverse Osmosis unit (RO), a water treatment unit, off and then on again. The bottom part shows how Cindy tried that solution the next time she got the same alarm.

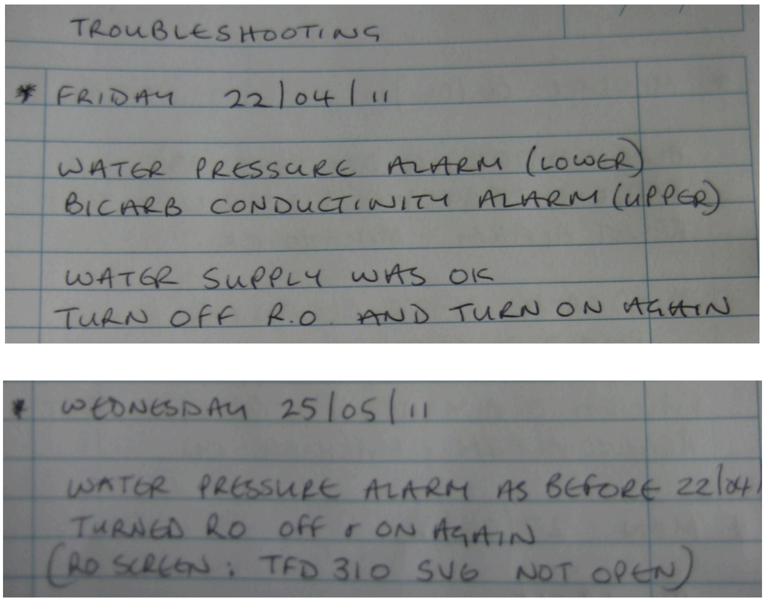


Figure 4.1: Cindy's recording of alarm solution in dialysis chart (top) and trying that solution next time (bottom)

An example of temporal distribution is Carl doing the machine's special disinfection programme, which needs to be done once every week, on the same day every week, Tuesday, so that he remembers to do it. DiCoT does not have an existing model that facilitates the analysis of such temporal distribution of cognition; the main study focused on the development of principles for the temporal distribution of cognition.

Some strategies are adopted by patients because of their individual knowledge, or lack thereof. For example, Alice developed a workaround of priming the dialysis circuit with the help of a syringe, instead of doing it through the machine, as she was unable to get it done that way. Some strategies are adopted because of a patient's values and preferences. For example, Alice dialyses on her verandah as it is a nicer environment. Because of its systemic focus, DCog does not provide suitable lenses for analysing these two types of strategies. However, since DCog is not restrictive as an approach, these types of strategies could be incorporated into the analysis, by creating additional codes for coding data for such strategies and issues.

4.7 Summary of this chapter

The preliminary study found that patients do adopt coping or optimising strategies when interacting with HHT, and that these interaction strategies are influenced by the context in which interactions happen. Also, cognition is distributed in the HH setting, through people, the physical environment, artefacts, and time. This indicates that DCog is a useful theoretical framework for studying interactions in that setting, especially when a key interest of the research is to understand how safety is achieved or compromised. The findings of the preliminary study have 6 main implications for subsequent phases of this research:

1. Interviews focusing on incidents should form the staple source of data on patients' interaction strategies and issues.
2. Since there is not one unique HHS being studied, but several instances of a system, one for each participant, the standard DiCoT approach of presenting one overall analysis in each model cannot be used in this research – instead, in each DiCoT model, several analyses should be done, one for each principle associated to that model.
3. To make sense of the complexity of the context, which involves broader systems influencing how patients' interact with HHT, the context should be represented in terms of several systems.
4. To facilitate the analysis of complex strategies, which involve several CFs, so as to progress to design implications, an analytical framework of CFs should be developed.
5. The preliminary study identified some strategies that involve cognitive processes distributed through time, in ways not discussed in the existing DCog literature. Subsequent study phases should capture more data on the temporal distribution of cognition in HH, and analyse that data to propose theoretical principles for such distribution of cognition.
6. The preliminary study identified some strategies that arise because of patients' individual knowledge or because of their values and preferences. These do not fall under the remit of DCog, but can be considered in the analysis by coding data for such strategies.

The work presented in this chapter has been published as:

Rajkomar, A., Blandford, A., & Mayer, A. (2012). Situated Interactions of Lay Users With Home Hemodialysis Technology: Influence of Broader Context of Use. *Proceedings of the 2012 Symposium on Human Factors and Ergonomics in Health Care* (pp. 215–219). Human Factors and Ergonomics Society.

Rajkomar, A., Blandford, A. & Mayer, A. (2013). Gathering data on patients' interactions with home hemodialysis technology. *Proc. CHI workshop 'HCI Fieldwork in Healthcare'*. ACM.

Rajkomar, A., Blandford, A. & Mayer, A. (2014). The ideal and the practical for studying patients' interactions with home haemodialysis technology. In Furniss, D., O'Kane, A. A., Randell, R., Taneva, S., Mentis, H., & Blandford, A. (Eds.), Fieldwork for Healthcare: Case Studies Investigating Human Factors in Computing Systems. *Synthesis Lectures on Assistive, Rehabilitative, and Health-Preserving Technologies*, *3*(1), 1–129. Morgan & Claypool.

4.8 Objectives of this research formulated after the preliminary study

After the preliminary study, based on the initial questions formulated for this research, and on the findings of the preliminary study, 5 objectives were set for the rest of this research. These correspond to the 5 contributions of this thesis. These objectives are:

- Methodological Objective 1, of developing an approach for doing the DCog analysis that helps to make sense of the complexity of the context of HH.
- The empirical objective of understanding the context in which patients interact with HHT, their interaction strategies and issues, and how the patient experience of interacting with HHT could be improved.
- Theoretical Objective 1, of assessing whether a DCog approach can facilitate the understanding of patients' situated interactions with HHT.
- Theoretical Objective 2, of developing principles for cognitive processes distributed through time.
- Methodological Objective 2, of developing an analytical approach for dealing with the complexity of strategies and the variability in strategies across participants, to help progress from analysis to design implications.

The first four objectives were addressed through a DCog analysis that was conducted across three phases of a main study. The next chapter gives an overview of the DCog analysis, and then subsequent chapters present the results of the DCog analysis in terms of the different models of DiCoT. The fifth objective was addressed through the development of CFA, presented later in Chapter 13.

Chapter 5: Overview & Methods of DCog Analysis

5.1 Introduction

This chapter gives an overview of the DCog analysis conducted in the main study across three study phases completed after the preliminary study. It describes the objectives of the DCog analysis, details the methods used for data gathering and analysis, and gives some background on the participants, on the dialysis machines used by them, and on the hospitals that participants belong to. Finally, it gives an overview of the main interaction strategies and issues identified in the DCog analysis.

5.2 Objectives of DCog Analysis

This section describes the 4 objectives of the DCog analysis, based on the questions formulated for this research, and on the related implications found during the preliminary study.

- The preliminary study found that broader systems influence how patients interact with HHT. Therefore, Methodological Objective 1 is to develop an approach for doing the DCog analysis that helps to make sense of the complexity of the context of HH. This objective will be addressed in Chapter 6, which presents the results of the analysis on system activities, by conceptualising the HH setting in terms of systems of activities. It is also revisited in Chapter 15, which reflects on the overarching approach used to apply DCog in this research.
- The preliminary study found that patients adopt coping and optimising interaction strategies when interacting with HHT, and that these strategies may be linked to safety implications or interaction design issues. The empirical objective is to further understand the context in which patients interact with HHT, their interaction strategies and issues, and how the patient experience of interacting with HHT could be improved. This objective will be addressed in chapters 6-12, which describe the context of interactions and report identified interaction strategies and issues. It is also revisited in Chapter 14, which reflects on the patient experience of interacting with HHT.

- The findings of the preliminary study indicate that cognition is distributed in the HH setting, physically, socially, artefactually, and temporally. Theoretical Objective 1 is to further investigate whether a DCog approach can facilitate the understanding of patients' situated interactions with HHT. This objective will be addressed in chapters 6-12, which show how cognition is distributed in the HH setting in different forms, and in Chapter 15, which reflects on the utility of DCog for studying interactions in a setting such as HH.
- The preliminary study found that cognition is distributed temporally in patients' interactions with HHT, and DiCoT does not have a model for analysing the temporal distribution of cognition. Therefore, Theoretical Objective 2 is to develop principles for cognitive processes distributed through time. This objective will be addressed in Chapter 12, which presents a new model of temporal structures.

5.3 Methods

After the preliminary study, a main study was conducted in three phases. In the first phase, data was gathered from 7 patients of H1 and 1 patient of H2. In the second phase, data was gathered from 8 patients of H3. In the third phase, data was gathered from 3 patients of H4. In each phase, the DiCoT principles were used to identify patients' interaction strategies and issues, by coding data in ATLAS.ti (Scientific Software Development, 2013). Table 5.1 below describes the details of these three phases and how they differed.

Table 5.1: Phases of the main study

Study Phase	Hospitals	Patients	Data gathering	Data analysis
1	H1, H2	Adam, Bob, Eric, Fiona, Gina, Ivan, Jill, Alice	• Observations, interviews, still pictures, video diaries • Each patient visited twice on average • Typical visit lasted 45 minutes	• Used 58 codes to code data
2	H3	Alex, Bea, Erica, Felix, Gary, Ida, Jim, Kevin	• Observations, interviews, still pictures • Each patient visited once • Typical visit lasted 90 minutes	• Used 62 codes to code data, including 4 new ones for the temporal distribution of cognition
3	H4	Abi, Beth, Eva,	• Observations, interviews, still pictures • Each patient visited once • Typical visit lasted 90 minutes	• Used 62 codes to code data

The strategies and issues across the three phases were consolidated into themes within each principle. The next section first explains why this study aimed to identify a broad range of interaction strategies, instead of seeking closure on certain strategies. Then, the following three sections describe the data gathering, data analysis and data validation methods, respectively.

5.3.1 Identifying a broad range of interaction strategies and issues across the three phases of the main study

This research aims to identify a broad range of interaction strategies and issues, by focusing on understanding the strategies and issues that come up in a particular patient's context. It uses ethnographic methods, and therefore focuses on getting qualitative insights, rather than getting closure on certain phenomena, getting saturation across participants, or generalizing behaviour. Therefore, an in-depth analysis was done for each participant, and the emphasis was on identifying interaction strategies and issues that happen in practice, even if a particular strategy/issue applied to only one participant of the study, and not on how many participants a particular strategy/issue was applicable for. Also, this research aims to identify strategies and issues across the different contexts of participants. This is why the results of the DCog analysis are presented across all three phases of the main study, instead of presenting the results of each phase separately. There are three main reasons for adopting this approach of identifying a broad range of interaction strategies: the research questions, the nature of the setting, and the constraints of data gathering.

Since there is very little literature that reports the interaction strategies and issues of renal patients with HHT, this research aims to identify a broad range of strategies and issues to inform the design of HHT, instead of focusing on a particular aspect of HHT design. Moreover, since the core contribution of this research is the application of DCog to understand situated interactions in HH, there is merit in showing the broad range of strategies and issues that can be identified through the use of DCog as a guiding framework.

The HH setting is characterized by variability in patients' contexts of interactions, and by the complexity of the treatment. The contexts of patients vary significantly, in terms of, e.g. physical setup, social setup, hospital arrangements, HHT used, extent of kidney failure, other medical conditions, age, literacy level, and level of experience with HHT. Therefore, it is likely that they face different issues and have different interaction strategies. It may therefore not be reasonable to seek closure on strategies; instead, it makes more sense to seek to understand the issues faced by patients in their specific contexts. HH is at an extreme of complexity, in terms of the sheer number of things a patient has to do for their treatment, and in terms of the implications of the social and physical intrusion of dialysis. Therefore, it is not practically possible to study how all participants perform all tasks involved in dialysis. When visiting a patient, given that limited time is available with them, it makes sense to focus data gathering on aspects of the treatment in which that particular patient faces issues.

Some constraints of data gathering in this research make the identification of a broad range of strategies and issues, instead of seeking closure on strategies, a logical choice. Firstly, as mentioned above, the researcher has limited time with a participant. Instead of using this precious time to check if all participants have a particular strategy, it is more useful to understand what strategies arise in their own contexts. Then, similar strategies can be grouped together at a fairly general level. Secondly, an interview with a patient becomes naturally geared towards the strategies of that particular patient, as they elaborate on their own issues. Also, because of the sensitivity of this setting, the participant 'owns' the interview in a sense – i.e. they are the patient, and the researcher is there to listen to their experiences, and not to just tick things on a list. It therefore makes more sense to engage with and understand the experiences of that particular patient, instead of systematically attempting to get cross-participant coverage of phenomena. This is reflected in the use of the critical incident technique in this research, which naturally implies focusing on the incidents that a particular participant had.

To summarise, considering the questions of this research, the nature of the HH setting, and the constraints of data gathering, an approach of identifying a broad range of strategies and issues across participants was chosen instead of an approach of seeking closure on certain strategies. The next section describes how data was gathered in the three phases of the main study.

5.3.2 Data gathering

In all three phases of the main study, data was gathered during visits to patients in the same ways as in the preliminary study, i.e. through short observations, still pictures of the physical environment in which the patient dialyses and of the patient's dialysis chart and other artefacts, and an audio-recorded, semi-structured interview with the patient. In most cases the carer participated in the interview as well. During the interview, participants were prompted to describe minor incidents they had had, through a simplified adaptation of the critical incident technique, as that proved to be an effective way of gathering data on patients' interaction strategies and issues during the preliminary study. In the first phase, participants were invited to keep diaries of incidents through loaned handheld video recorders or pen and paper. Like in the preliminary study, this did not work, and was discontinued in the second and third phases. In all, 19 patients, 3 home nurses, 3 renal technicians, and 1 nephrologist participated. Brief profiles of participants are given later in section 5.4.

The first phase of the main study included the data collected during the preliminary study, i.e. data from 4 patients of H1 and 1 patient of H2, data from further visits to the participants of the preliminary study, and data from new participants. The 4 patients of H1 who participated in the preliminary study were visited again: Adam, Cindy and Fiona were visited one more time, while Carl was visited two more times. Additionally, 3 other patients were visited: Gina, Ivan, and Jill. Gina and Ivan were visited twice, while Jill was visited once. Nancy, the home nurse of H1, was interviewed once more, and one renal technician, Terry, was interviewed.

The 8 patients of the first phase of the main study were visited two times in all, except for Carl who was visited 3 times and for Jill who was visited once. The purpose of the follow-up visit was to obtain clarifications on data from the first visit, and to see whether the patient had experienced any new issues. Two different home visit guides were used: one for the first visit, and another one for the follow-up visit. The one for the first visit was the same home visit guide used in the preliminary study, but with new questions to elicit data on patients' interactions with HHT during troubleshooting, as the preliminary study found that patients seemed to struggle most with interactions during troubleshooting. Also, some questions were added to elicit data on patients' temporal patterns, to address Theoretical Objective 2, of understanding the temporal distribution of cognition in patients' interactions with HHT. Appendix D section D.1 shows the home visit guide for the first visit. The home visit guide for the follow-up visit consisted of participant-specific questions focusing on getting clarifications from the participant, based on the analysis of the data gathered during the first visit to that participant, and also sought to check whether the participant had had any new experiences of interest since the first visit. Appendix D section D.2 shows the home visit guide for the follow-up visit to Ivan, as an example.

The second phase of the main study was conducted with 8 patients, 1 home nurse and 1 renal technician, all of H3. During the first phase, it was found that arranging for follow-up visits was problematic for some patients. Hence, follow-up visits were not done as from the second phase. Instead, longer interviews were conducted, to obtain clarifications on phenomena as they were being reported.

The third phase of the main study was conducted with 3 patients, 1 home nurse, 1 renal technician, and 1 nephrologist, all of H4.

5.3.3 Data analysis

Data was analysed by coding phenomena with the DiCoT principles, in ATLAS.ti, and by analysing pictures and sketches of the physical layout and of artefacts. One finding of the preliminary study was that the DCog analysis had to be done in a way that reflects that there is a different system instance for each participant. Therefore, in each of the three phases of the main study, the standard DiCoT approach of presenting one overall analysis in each DiCoT model was not used; instead several analyses were done, one for each principle associated with that model. In this way, patients' interaction strategies and issues can be presented without an implicit generalization of the context across all participants.

Data analysis in the first phase of the main study was conducted in the following steps:

1. The interview done during the first visit to the participant was transcribed and observation notes were typed up. These documents were then loaded into ATLAS.ti. An example of an interview transcript (for Jill) and an example of observation notes (for Ivan) are in Appendix D section D.3.
2. These documents were coded for phenomena, including incidents and issues, related to the DiCoT principles. An overview of these principles will be given later in section 5.7. The documents were also coded for more general phenomena at the level of the HHS, and for issues involving broader systems

(HS, DUS, and SS). 58 codes were created in ATLAS.ti, including 2 codes for the temporal distribution of cognition, and 1 code for phenomena related to patients' individual knowledge and their values and preferences. A list of the codes and an example of a coded interview transcript (for Ivan) are in Appendix section D.4. Through this approach, of coding data for phenomena that inform on patients' interaction strategies and issues, the DiCoT analysis can be conducted with interviews as the main source of data.

3. At the end of the coding process, a document containing all the quotations (coded sections of a document) for that participant was generated. An example of this document (for Jill) is in Appendix D section D.5.
4. Then, each quotation in the quotation document was paraphrased in an analysis document that was structured hierarchically in terms of DiCoT model → DiCoT principle → Participant. The purpose of this document was to group insights for a particular principle across all participants. Appendix D section D.6 shows how one quotation from the example quotation document referred to in the last step has been paraphrased in the analysis document.
5. Then, any still pictures of the physical layout and of artefacts that were taken for this participant were analysed, and insights related to the DiCoT principles were noted in the analysis document. An example of an entry in the analysis document based on the analysis of a picture (for Adam) is in Appendix D section D.7.
6. If there was an open point about a quotation or a picture, i.e. clarification from the participant was required, a note was made in the home visit guide for the second visit for that particular participant. An example of a point for clarification during the second visit (for Ivan) is in Appendix D section D.8.
7. Steps 1 to 6 were repeated with the data gathered during the second visit to the participant, and clarifications obtained for questions raised in step 6 were noted in the analysis document. An example of an entry of a clarification into the analysis document (for Ivan) is in Appendix D section D.9.

After the above analysis was completed for each participant, the contents for each DiCoT principle in the analysis document were analysed, to identify different themes within each principle. The phenomena that had been coded with the two codes for temporal distribution of cognition were reviewed to identify common patterns across them. This resulted in the identification of six principles: temporal layouts, temporal assignments to tasks, dealing with anticipated problems, distribution of a task plan, reducing peak complexity, and time for action. New codes for these principles were then created and used in the second and third phases.

Data analysis in the second and third phases of the main study was similar as in the first phase, except that there was only one set of documents for each participant, as each participant was only visited once. Also, new codes were used for coding strategies and issues related to the temporal distribution of cognition, to patients' individual knowledge, and to their values and preferences. For each phase, at the end of the coding process, the quotations were analysed to identify themes within each DiCoT principle, as in the first phase. Phenomena pertaining to themes already identified in the first phase were added to the existing themes in the analysis document, and new themes were created where required. Due to the large number of quotations, not all quotations were paraphrased when they were added to the analysis document. For some quotations, only the reference number of that quotation in ATLAS.ti was added.

At the end of the third phase, the themes within each DiCoT principle were consolidated, to produce one table for each principle. The table lists the different strategies and issues (each being a theme) and examples of those from the data. In all, 26 tables were created. These are tables E.1 to E.26 in Appendix E, and they will be referred to in subsequent chapters. Table 5.2 below shows part of Table E.4, which reports on interaction strategies and issues related to communication channels.

In all, the data for the DCog analysis consisted of 35 interview transcripts, 21 observation notesheets and 190 still pictures. 1345 quotations were created in Atlas.ti. 282 interaction strategies and issues were identified across 26 principles.

Table 5.2: Snapshot of Table E.4, which reports on interaction strategies and issues related to communication channels

	Strategy/Issue	Example(s)
1.	Patient/carer introducing new communication channel to maintain patient-carer communication while carer is elsewhere in the home	• Alex installed an intercom system to be able to communicate with his wife who is downstairs while he dialyses. IMG_1313.JPG • So that Bob can call him in case of a problem during dialysis, while Carl is upstairs doing things, Carl bought a walkie-talkie set. Bob has used the walkie-talkie on some occasions when he was having cramps and neither his son nor wife was in the room. Carl: "Yes, you know, sometimes I go down, my mum's downstairs, to get some tea or something. He calls, yes. He calls to say that he's suffering from cramps. Because my dad panics, so he needs to have it. Somebody always needs to be there; we can't leave him alone, he doesn't like it. If I'm not there, my mum's there, okay. Or if both of us are out of the room, the walkie-talkie is there, so he does call, yes, if he wants anything, yes." • Beth: 62:18: uses buzzer and beeper to call carer to bring drink and biscuits or when there is an alarm. He can sometimes hear alarm himself, but not if he is watching football for example. • Eva: has alarm set, can call son with it, who goes downstairs and does his things during dialysis (like a phone thing, which has a base. She has phone and he takes base with him). 67:13: used alarm set to call son, e.g. last week when she wasn't feeling well, he came upstairs and eventually took her off machine.
2.	Patient having backup communication channel in case particular channel fails	• Garry has an extra emergency landline phone, in case there is a power cut and his digital phone does not work (there are frequent power cuts in his region when it is stormy)
3.	Nurse getting to know of more issues during home visits, in which communication happens face-to-face and at dialysis site	• Nancy considers her visit to the home very important, as it allows her to discover problems that a patient has while using the machine that she would not get to know of otherwise. E.g. she helped Ivan with problems a couple of times while she visited – he didn't call her about these problems as he "didn't want to bother her". On one occasion Ivan's machine was in a wrong disinfection mode (though he hadn't been taught how to do the special weekly programme yet), and he couldn't understand why it kept asking him for a special cartridge. • ....

5.3.4 Data validation

As mentioned in Chapter 3, data validation is achieved through the groundedness of the analysis in the data, through triangulation, and through inspection. The analyses in this research seek to understand interaction issues faced by patients, through a patient-centred approach, and these issues are self-validating in a sense. They are natural indicators of what could be improved in system design to improve the patient experience. Data was gathered through different sources, namely interviews, direct observations and artefact analysis, and from different parties (patients, carers, home nurses, technicians and nephrologist), providing for triangulation. Also, the exact process followed during data analysis and samples showing how the analysis was done have been provided for inspection. Member checking was used only in the first phase of the main study, to help the researcher build domain knowledge in a new domain. During a second interview with the home nurse, the home nurse validated a flowchart that was produced to capture the processes involved in HH. Appendix D section D.9 shows the flowchart that was validated. The next sections describe the background of the participants, machines, and hospitals involved in the main study.

5.4 Background of participants

Table 5.3 below describes the backgrounds of the patients who participated in the main study. Participants are referred to by fictitious names. The following convention has been used when naming participants: a name starting with C refers to a carer, a name starting with D refers to a doctor, a name starting with H refers to a helper, a name starting with N refers to a nurse, a name starting with T refers to a technician, and a name starting with any other letter refers to a patient. For the sake of simplicity, only carers and helpers who are referred to in the narrative of the thesis have been assigned names.

A carer is someone who has received some training on caring for the patient, and their involvement can vary from only intervening in case help is needed, to helping the patient with the needling at the beginning and end of treatment, to setting up the machine and programming the treatment. A helper is someone who has not received training on caring for the patient, but occasionally helps with some aspect of the treatment, e.g. handing items to the patient when required, starting the disinfection process on the machine, or intervening in case of emergency. The persons who participated in the study either by being observed or by being interviewed are highlighted in bold. Time 'On Dialysis' and time 'On HH' are given up to the date of my first visit to the patient. The participants belong to 4 different hospitals, referred to as H1, H2, H3 and H4. The first phase of the main study was conducted with the 7 patients of H1 and the 1 patient of H2. The second phase was conducted with the 8 patients of H3. The third phase was conducted with the 3 patients of H4. The patients are listed in order of participation in the study. Among them, they use 5 different machines, referred to as M1, M2, M3, M4 and M5. The machines are described briefly in the next section.

Table 5.3: Background of participants

Name	Gender	Age	Carer	Helper	Other Conditions	Lives with	On Dialysis	On HH	Hospital	Machine
Adam	M	38	-	Hillary (wife)	Diabetes	Wife, Son	3 yrs	4 wks	H1	M1
Bob	M	77	**Carl (son)**	Heidi (wife)	Heart disease	Wife	1 yr	3 wks	H1	M1
Eric	M	72	**Cindy (wife)**	-	Paraplegic, diabetic	Wife, 2 Sons	2.5 yrs	3 mts	H1	M1
Fiona	F	26	-	-	-	-	13 yrs	1.5 yrs	H1	M2
Gina	F	65	-	-	-	-	15 yrs	10 yrs	H1	M2
Ivan	M	77	-	**Helen (wife)**	Heart attack, has pacemaker	Wife	8 yrs	3 wks	H1	M1
Jill	F	47	-	Hanna (mother)	Arthritis	Parents	27 yrs	10 yrs	H1	M2
Nancy									H1	
Terry									H1	
Alice	F	37	-	Partner, Daughter	-	Partner, Daughter	17 yrs	1.5 yrs	H2	M3
Alex	M	72	Wife	-	Ileostomy, lame, heart attack, prostate problems, parathyroid problems	Wife	2.5 yrs	2 yrs	H3	M4
Bea	F	63	**Husband**	-	-	Husband	4.5 yrs	3 yrs	H3	M4
Erica	F	64	**Husband**	-	Diabetes	Husband	No info	9 mts	H3	M5
Felix	M	56	-	Wife	-	Wife	3 yrs	1.5 yrs	H3	M4
Garry	M	43	Wife	-	Hernia problem	Wife	2.5 yrs	1.5 yrs	H3	M3
Ida	F	54	**Husband**	-	-	Husband	1 yr	1 yr	H3	M3
Jim	M	65	**Wife**	-	-	Wife, Daughter	4 yrs	2 yrs	H3	M5
Kevin	M	24	-	Mother	-	Parents	3 yrs	2 yrs	H3	M3
Nelly									H3	
Ted									H3	
Abi	F	41	-	**Mother**	Impaired vision	-	18 yrs	8.5 yrs	H4	M5
Beth	F	Late 60s	**Husband**	-	Prosthetic leg	Husband	35 yrs	30 yrs	H4	M5
Eva	F	67	**Son**	**Daughter-in-law**	Diabetes, impaired vision	Husband, Son, Daughter-in-law	6 yrs	1 mt	H4	M5
Neal									H4	
Tom									H4	
David									H4	

5.5 Background of HH machines

Five different HH machines are used across the 19 patients of this research, due to different hospitals deploying different machines to their home patients. M1 is a relatively recent machine, recently introduced by H1 at the time of the study, and is used by 4 participants. M2 is an older machine, used by earlier patients of H1, and is used by 3 participants. M3 is a relatively recent machine used by some patients of H2 and H3, and is used by 4 participants. M4 is an older machine, used by some earlier patients of H3, and is used by 3 participants. M5 is the successor of M4, and is used by some recent patients of H3 and by patients of H4. M5 is used by 5 participants. M1, M2, M4 and M5 are not portable, require fixed plumbing and water arrangements, and are relatively big. M3 is portable, does not require special water arrangements, and is relatively small in size. However, M3 is not suitable for all patients, particularly for those who require more extensive dialysis. Figures 5.1-5.5 below show the different machines.

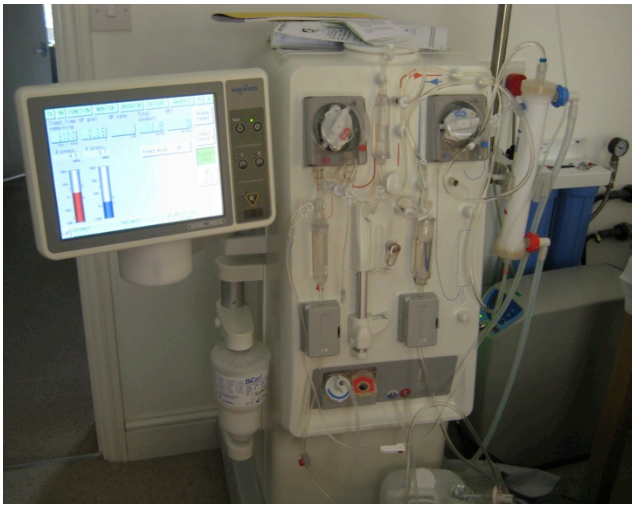


Figure 5.1: Home Haemodialysis Machine M1

Figure 5.2: Home Haemodialysis Machine M2

Figure 5.3: Home Haemodialysis Machine M3

Figure 5.4: Home Haemodialysis Machine M4

Figure 5.5: Home Haemodialysis Machine M5

The interface designs of these machines differ significantly: M1 and M5 are modern and consist of touchscreens; M2 and M4 consist of physical buttons and visualisations (e.g. graphs); and M3 is simpler, consisting of physical buttons and numbers shown on displays. The machines also differ in how they are used, in terms of the steps involved in using them, but also in terms of the type of dialysis performed. For example, participants using M5 perform haemodiafiltration instead of standard haemodialysis. Haemodiafiltration involves the infusion of ultra-purified water directly into the patient's blood, and requires water of a higher purity than standard dialysis. There are also variations in hospital practices related to the use of the machines. For example, M1 also supports haemodiafiltration, but H1 prefers not to perform haemodiafiltration. The next section elaborates on some differences among the hospitals.

5.6 Background of hospitals

There are variations in HH practices among the different hospitals involved in the main study. Note that H2 did not formally participate in the study, and no data was gathered from hospital staff members of H2. The limited data on the practices of H2 is from the visit to Alice, the only participant from H2.

Some differences in practices naturally emerge because of the different machines in use by the different hospitals. Other differences in practices are because of differences in policies or beliefs in what the current best practices in HH are. For example, H1 does 'sodium profiling' with its patients, which means that the nephrologist may request the patient to adjust the level of sodium used in the preparation of the dialysate solution depending on how the patient feels. In contrast, H3 and H4 do not do sodium profiling, as according to them it is not a good practice to do so. Some other differences include: the type of dialysis performed; the duration of the patient's training in the dialysis unit; the level of involvement of the home nurse in the patient's treatment at home; whether a patient who lives on their own is allowed to go on HH; the arrangements for support from nurses/technicians outside of the dialysis unit hours; the configuration of how responsibilities are shared between the home nurse and the technician; and whether the Renal Patient View system is used, so that the hospital can upload blood test results for the patient to see online, after a sample of the patient's blood, collected either when the nurse visits the patient at home or when the patient visits the hospital, has been analysed in the hospital.

This research aims to understand patients' interaction strategies and issues in a range of contexts, and not to compare the patient experience of using the different machines or of the different hospitals. The differences in machine design and in hospital practice are seen as extra dimensions of variability in the context of interactions. Hence, in the rest of the thesis, differences among the machines and among the hospital practices are highlighted only where deemed relevant for the analysis. The next section gives an overview of the DCog analysis, in terms of the main strategies and issues identified.

5.7 Overview of DCog analysis

The empirical objective of the DCog analysis is to understand the contexts in which patients interact with HHT, and their interaction strategies and issues. Chapters 6 to 12 present the results of the analysis, each focusing on one DiCoT model. Table 5.4 below gives an overview of the analysis, in terms of some of the main strategies and issues identified for each principle of each DiCoT model. The distinction between a strategy and an issue is that, while a strategy identifies a particular way of interacting with HHT, and naturally points to a problem in the system if it is a coping strategy, an issue simply describes a problem in the system without identifying a particular way of interacting with HHT. For example, for Principle 4 in Table 5.4, "Introducing extra communication channel between patient and carer so carer can be in other parts of the home during dialysis" is a strategy, whereas "Ambiguity on whether the nurse or the technician should be contacted for a problem" is an issue. Throughout the thesis, for the sake of simplicity, I refer to them collectively as 'interaction strategies and issues' when not discussing a specific strategy or issue.

Out of the 26 principles listed in Table 5.4, 14 principles are from Furniss & Blandford (2006). These are principles 4 to 7, 10, 11, and 13 to 20. 3 of the principles, namely 1-3, are from Rajkomar & Blandford (2012). Note that these 3 are perhaps better described as meta-principles than as principles, as their purpose is to help describe the context, in terms of the systems, activities, and tasks that constitute it. I include them in this list of principles as I use them to structure the analysis of interaction strategies and issues that do not fall under the other principles and that are related to the broader context of interactions. 6 principles, namely 21-26, were developed in this research to help understand how people distribute cognitive processes over time. 3 principles, namely 8, 9 and 12, are not DCog principles, and they pertain to phenomena that fall outside the typical remit of DCog. I include these principles in this list as I use them to structure the analysis of phenomena related to them, to get a richer picture of patients' interaction strategies and issues. Note that, though principles 8 and 9 do not pertain to social phenomena, as they focus on the individual, I include them under the Social Structures Model, as both the two principles and the model focus on the human aspects of a system.

Table 5.4: Overview of DCog analysis

Principle		Main Strategies and Issues Identified
System Activity Model		
1.	Systems	• Dialysis affecting home activities and vice versa • Support arrangements with dialysis unit influencing how patient does their dialysis • Dialysis influencing activities in broader society and vice versa
2.	Activities	• Dialysis itself decreasing ability of patient to do things • Other medical conditions affecting how a patient's dialysis is done • Results of other activities or errors within them affecting dialysis
3.	Tasks	• Needling most problematic part of treatment for several patients
Information Flow Model		
4.	Communication Channels	• Introducing extra communication channel between patient and carer so carer can be in other parts of the home during dialysis • Ambiguity on whether the nurse or the technician should be contacted for a problem • Lack of comm. channel between dialysis unit and the patient's machine
5.	Information Transformation & Decision Hubs	• Difficulty for carer to ascertain current state of patient when patient is asleep
Social Structures Model		
6.	Shared Goal Structure	• Taking measures to get help from other people if needed, when alone • Helper with no training interacting with HHT
7.	Development and Retention of Knowledge	• Patients supporting each other in the learning process • Limitations of training – some problematic situations cannot be replicated for training purposes
8.	Individual Knowledge	• Adopting workarounds to avoid performing some operations for which they feel they lack knowledge. • Optimizing strategies patient can adopt because of knowledge they have
9.	Values and Preferences	• Optimising on peacefulness and comfort
Physical Layout Model		
10.	Physical Layouts	• Carer coming close to dialysis room so they can be within verbal communication reach of patient • Machine as an intrusion into the HS: having a secluded 'hospital room' or concealing the machine • Dialysing in bedroom conflicting with bedroom as part of HS
11.	Arrangement of Equipment	• Limitations of physical environment of home, as compared to dialysis unit, creating new extraordinary situations
12.	Physical Ergonomics	• Patient having trouble comfortably reaching their machine • Physical buttons and clamps of machine hard to press • Difficulty with fiddly tasks such as manipulating syringes and supplies
13.	Space and Cognition	• Using spatial layout to remember to do a task
14.	Physical Naturalness	• Creating physical representations • Reduced colour-coding in line parts making it harder to distinguish ends
15.	Situation Awareness & Horizon of Observation	• Patient using visual and auditory elements of physical environment to help them perform certain steps or deal with some situations, e.g. visibility of blood's colour
Artefact Model		
16.	Coordination of Resources	• Patient forgetting to do a particular step when coordinating resources themselves

		• Machine pointing out that something is wrong, but not helping patient in finding cause of problem • Coordination done by machine perceived as unnecessary/annoying
17.	Representation-Goal Parity	• Using representation on interface when dealing with pressure alarms • Machine's message not understandable or does not guide on course of action
18.	Mediating Artefacts	• Creating externalisation of plan to allow untrained person to start disinfection • Adapting existing artefact to make it easier to use or more effective
System Evolution Model		
19.	Cultural Heritage	• Dialysing in living room, so children can learn about the treatment
20.	Expert Coupling	• Long-time patients dialysing on weekend, despite no support being available from dialysis unit • Long-time patients sleeping while dialysing or dialysing overnight
Temporal Structures Model		
21.	Temporal Layouts	• Optimising on time spent on the dialysis activity
22.	Temporal Assignments to Tasks	• Doing special disinfections or drug injections on specifically assigned days
23.	Dealing with Anticipated Problems	• Checking blood sugar level before dialysis to help assess cause of symptom later • Preparing dialysate batch in advance with M3 in case it fails • Doing dialysis tasks before anticipated decline in cognitive resources
24.	Distribution of Task Plan	• Forgetting a step when rushing, and allowing more time for a task
25.	Reducing Peak Complexity	• Preparing dialysis tray in advance
26.	Time for Action	• Spatiotemporal relationships for when medication needs to be taken • Missing cue for preparation for disconnection, and technotemporal cueing

The context of HH is complex. It does not comprise one clearly bounded socio-technical system – there are several systems at play. To allow a structured analysis, the next chapter makes sense of the context in terms of several systems, through the System Activity Model.

Chapter 6: System Activities

6.1 Introduction

This chapter describes the HH setting in terms of the systems, activities, and tasks involved, through the System Activity Model (Rajkomar & Blandford, 2012). This model is a meta-model that helps to scope and focus analysis in the subsequent DiCoT models, and helps to understand influences on interactions from the broader context. It helps to make sense of the complexity of the context, by defining the socio-technical system being studied in terms of a primary activity, which is the focus of the study, the tasks that happen within it, and other secondary activities that are also part of the system. This allows a clear scope to be defined for the analyses done in the other DiCoT models, i.e. the scope will be the primary activity, and this facilitates the understanding of influences from the secondary activities on the primary activity. In the ICU setting studied by Rajkomar & Blandford (2012), the context could be conceptualized as a single socio-technical system, i.e. the ICU, consisting of different activities happening within it. Therefore the System Activity Model in that study served only to describe the different activities happening in one system, and then the tasks in one particular activity of interest, infusion administration. However, in the case of this study, the context that influences how patients interact with HHT consists of several systems, and not just one clearly bounded socio-technical system. Therefore the analysis done through the System Activity Model in this study first seeks to define these systems, then the activities within the main system of interest (HHS), and then the tasks within the primary activity of interest of that system (Dialysis activity).

The objectives that this chapter addresses are:

1. Methodological Objective 1, of developing an approach for doing the DiCoT analysis that helps to make sense of the complexity of the context of HH. This is achieved by scoping the DiCoT analysis in terms of systems, activities, and tasks. As discussed in Chapter 4, it is not amenable to represent the context that influences how patients interact with HHT in terms of a single system.
2. The empirical objective of understanding the context in which patients interact with HHT and their interaction strategies and issues. The analysis

in this chapter describes the context of HH in terms of systems, activities, and tasks, and presents some interaction strategies and issues related to the broader context.

The next sections respectively focus on the systems that constitute HH, the activities within the HHS, and the tasks within the Dialysis activity.

6.2 Systems constituting home haemodialysis

The context that influences how patients interact with HHT consists of several systems, and not just one clearly bounded system. I view a system as a logical unit that exists to perform a specific function, and is differentiated from other systems by the function for which it exists. A system may also have a sub-system, which exists to fulfil part of the function of the larger system. From this perspective, there are five distinct systems representing the context in which HHT is used in this study: Technology System (TS), Home Haemodialysis System (HHS), Home System (HS), Dialysis Unit System (DUS), and Society System (SS). These systems are shown in Figure 6.1 below, followed by a summarized description of each system in Table 6.1. For the sake of simplicity, the figure only shows systems, and excludes activities, people and artefacts. The HHS, underlined in Table 6.1, is the system that this research focuses on.

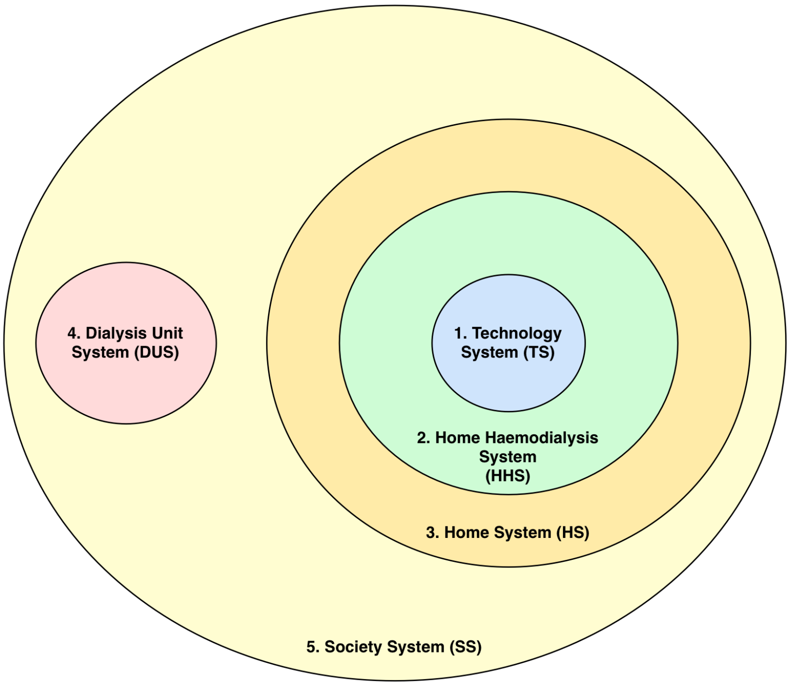


Figure 6.1: The context of home haemodialysis in terms of different systems

Table 6.1: Systems constituting the home haemodialysis context

System	Summary
1. Technology System (TS)	This system exists specifically to provide dialysis treatment to the renal patient via the machine, i.e. to clean the patient's blood and remove excess fluid. It consists of the HH machine and other technical components such as the water purifier, also known as the RO (Reverse Osmosis) unit, and the water softener. The water purifier treats domestic water so it is suitable for mixing with the dialysate solution, and the water softener softens the water that is fed to the water purifier to protect the membrane of the purifier. The TS is a sub-system of the HHS.
2. Home Haemodialysis System (HHS)	This system exists specifically to provide renal replacement therapy to a renal patient. It consists of the TS, and additionally a number of actors and artefacts. The function of the HHS, i.e. providing renal replacement therapy to a renal patient, is composed of many sub-functions, for which patients perform different activities to fulfil – dialysing with the machine is just one of these activities. The HHS can be seen as a sub-system of the HS, as most of it exists physically within the HS.
3. Home System (HS)	This system provides a place of residence to a family, including providing the physical and social environment required for the family to perform a number of activities. If a family member is a renal patient, then an extra sub-system, the HHS, exists within the HS. Note that, a certain family member would be considered part of the HHS only if that family member was somehow involved in the treatment of the patient, e.g. by being a carer. A child, for example, would belong to the broader HS, but not to the HHS.
4. Dialysis Unit System (DUS)	This system exists to provide haemodialysis treatment to patients who visit the unit, and also to provide support to HH patients when required. E.g. a patient can call staff at the unit in case of problems with their dialysis, or they can arrange to dialyse in the unit if their machine at home is not functioning. For the purpose of the analysis in this study, it is considered as a system that is separate from the HHS, but which supports the latter.
5. Society System (SS)	This all-encompassing system consists of the HS, the DUS, and, importantly, for the analysis in this study, of other patients and other clinical staff belonging to other hospitals and dialysis units. It can also be seen as the system in which the activity of employment happens, for a patient who is employed.

This research focuses on understanding how patients interact with HHT, in the HHS, specifically during the Dialysis activity. However, the analysis done in Chapter 4 showed that the other systems in the broader context all influenced patients' interactions with HHT.

Appendix E Table E.1 reports on 14 interaction strategies and issues related to these broader systems. I discuss some of the main strategies and issues next. There are interactions between the Dialysis activity of the HHS, which is the focus of this study, and activities of the other systems. As an example of the Dialysis activity affecting an activity of the HS, Adam plans his dialysis so that the machine's noise does not disturb the sleep of his young child. Conversely, activities of the HS can affect the Dialysis activity. For example, several patients get low water pressure alarms during their dialysis when someone else in the home is doing an activity that uses water at high pressure, e.g. showering, laundry or watering the garden.

The support arrangements with the DUS can influence how patients do their dialysis at home. Several patients avoid dialysing at times when the DUS is closed, e.g. on the weekend, as they may not be able to get adequate support in case a problem happens during dialysis. Also, the perceived difficulty/inconvenience of a home patient arranging to get dialysed in the unit led some patients/carers to attempt to fix problems with the machine on their own, instead of waiting for the technician's visit, so they could continue dialysis at home.

Doing the Dialysis activity at home allows some patients to have a job, which can be seen as an activity of the SS. As an example of an interaction between the two activities, Garry, who works as a chef, once bled for two days when he cut himself, because of the anticoagulant that is used during dialysis. Going on holiday can be seen as another activity of the SS. Some patients take their portable machines with them on holiday, and others arrange to dialyse in another dialysis unit in the country or abroad, so they can simultaneously be on holiday and perform dialysis. The strategies and issues presented above highlight the need to design HHT such that it fits with the activities happening in the broader systems that the patient is part of. This section described the different systems constituting the context of HH; the next section describes the HHS in more detail, outlining the different activities within that system that patients have to perform for their renal replacement therapy.

6.3 Activities within the Home Haemodialysis System

Within the HHS, 9 activities were identified, shown in Figure 6.2 below: 1) Dialysis; 2) Monitoring Renal Disease; 3) Coordination with Clinical Staff; 4) Medication Management; 5) Coping with Other Conditions; 6) Lifestyle Management; 7) Infection Control & Disposal; 8) Stock Management; and 9) Technical Maintenance. These activities each achieve a sub-goal of the overall system goal of providing renal replacement therapy to a patient. The Dialysis activity, the focus of this study, is expanded and shows the actors involved in it: the patient, the carer, the helper, the nephrologist, the home nurse, and the technician. To perform the Dialysis activity, the patient uses the TS and other artefacts. Table 6.2 summarises these 9 activities. The Dialysis activity, underlined in Table 6.2, is the activity that this study focuses on.

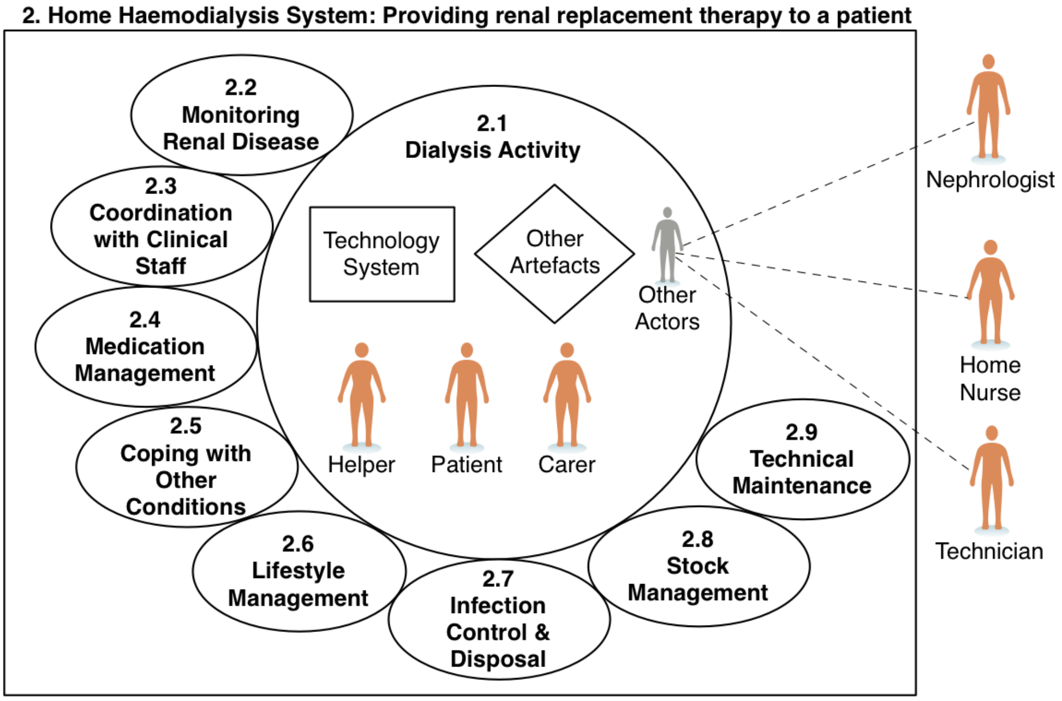


Figure 6.2: Home Haemodialysis System in terms of its activities, with the Dialysis activity expanded

Table 6.2: Activities within the Home Haemodialysis System

Activity	Summary
2.1. Dialysis	This research focuses on this activity, which consists of using the machine in dialysis sessions to clean the patient's blood and remove excess fluids. The main actors in this activity are: the patient, the carer or helper if applicable, the nephrologist, the home nurse and the technician. To perform dialysis, the patient uses the TS and other artefacts (e.g. weighing machine).
2.2. Monitoring Renal Disease	The patient needs to continuously monitor their health, and, depending on how they feel and the symptoms being experienced, they may need to adjust their dialysis treatment accordingly.
2.3. Coordination with Clinical Staff	The patient has to coordinate with the nurse and nephrologist on a regular basis to review the patient's treatment and make required adjustments to the dialysis prescription, medications, or diet. Typically, a patient visits the hospital or is visited by the home nurse once in a month to submit blood samples taken before and after dialysis, which are analysed to assess the patient's condition. On an on-going basis, if problems arise with the patient's condition or with their treatment, the patient or carer contacts the home nurse for support.
2.4. Medication Management	Renal patients typically need to take several drugs and supplements. Some drugs are taken routinely, e.g. on a daily basis, independent of the time at which a patient dialyses, while other drugs need to be taken in coordination with dialysis sessions, either before, during, or after a particular session. The intake of these different drugs needs to be managed by the patient.
2.5. Coping with Other Conditions	Some renal patients also have other conditions, which they need to deal with and which may also influence how their dialysis treatment is done, e.g. cardiovascular conditions and diabetes.
2.6. Lifestyle Management	Based on a patient's particular condition, that patient has to follow a certain diet, to provide deficient nutrients and counter some effects of dialysis, and carefully manage fluid intake, since the patient's body cannot get rid of fluids in a normal way.
2.7. Infection Control & Disposal	Before and after dialysis, the dialysis machine needs to be disinfected through a built-in disinfection operation. Besides that, the patient needs to maintain a high level of hygiene in the dialysis room to prevent infections. This includes cleaning the room regularly, wiping surfaces, wiping certain parts of the machine, and bleaching the waste lines. Moreover, supplies used during dialysis are treated as clinical waste, and need to be stored appropriately in yellow bags or sharp bins. The patient then needs to coordinate with the city council to arrange for disposal of these.
2.8. Stock Management	The stock of medical and dialysis supplies that is kept in the patient's home, which consists of many different items and is physically bulky, needs to be managed, both in terms of the physical management of the stock within the home, e.g. moving supplies from a main stock in a shed to a mini-stock in the dialysis room, or arranging stock in order of date to use older stock first, and in terms of ensuring that there are enough supplies, by coordinating with delivery staff for replenishments when required.
2.9. Technical Maintenance	This refers to the technical maintenance of the dialysis machine and other technical components. Some of it can be done by the patient, e.g. changing the water filter in the machine, either when prompted by the machine or after a certain amount of time, and some of it is done at regular intervals by the technician. This also refers to the fixing of technical problems that arise in between planned maintenances. Additionally, for patients doing online haemodiafiltration, they need to extract a water sample every month for a water quality check, and some of them perform a litmus test of the water every time they dialyse.

Defining these activities within the HHS helps to scope subsequent analyses in the other DiCoT models. Another reason for defining all these activities, when the focus of the study is on one of them, in this case the Dialysis activity, is that these other activities play important roles in fulfilling the overall function of the HHS, and the description of these activities helps to understand the broader context in which patients interact with HHT. Additionally, they may influence the primary activity, as discussed next.

Appendix E Table E.2 reports on 10 interaction strategies and issues related to the activities with the HHS. I discuss some of the main strategies and issues next. Firstly, the haemodialysis treatment itself typically decreases the ability of the patient to do things during the Dialysis activity, as the treatment restricts their movements and affects the physiology of the patient. For example, Kevin reported that his “brain goes funny” during dialysis and he cannot concentrate. Therefore, HHT should be designed with these potential side effects of the treatment in mind.

Secondly, other medical conditions may affect how a patient’s dialysis is done. For example, Bob, who has heart conditions, has to adjust the blood pump speed on his machine such that it is a compromise between having efficient dialysis (through a higher pump speed) and not causing too much stress on his cardiovascular system (through a lower pump speed). Another example is that Jill, with arthritis in the hands, has difficulty manipulating clamps on the machine and syringes. This highlights the need to consider the restrictions imposed by other conditions that the patient may have when designing HHT.

Thirdly, the results of other activities or errors that happen within them can affect the Dialysis activity. For example, once Carl didn’t keep an eye on the stock of supplies, and Bob could not dialyse when he wanted, as they had run out of saline. Another example is the link between the Lifestyle Management activity and the Dialysis activity. Sometimes patients struggle to identify their dry weight, the target weight to be reached at the end of dialysis, because of fluctuations in their weight. This highlights the potential for next-generation HHT to improve the patient experience; the technology could provide some form of integrated support for these other activities. This section described the different activities within the HHS; the next section details on the tasks in the Dialysis activity, which is the focus of this study.

6.4 Tasks within the Dialysis activity

The Dialysis activity can be seen as consisting mainly of 23 tasks, which essentially involve the preparation of the patient and the machine for dialysis, recording physiological measurements, starting the dialysis, attending to alarms and patient reactions, injecting required drugs, and terminating the dialysis session. Figure 6.3 below shows a typical temporal layout of these tasks. Appendix A Table A.1 describes these tasks. The tasks and their order vary, depending on the machine a particular patient uses, their hospital's policies, and their own preferences.

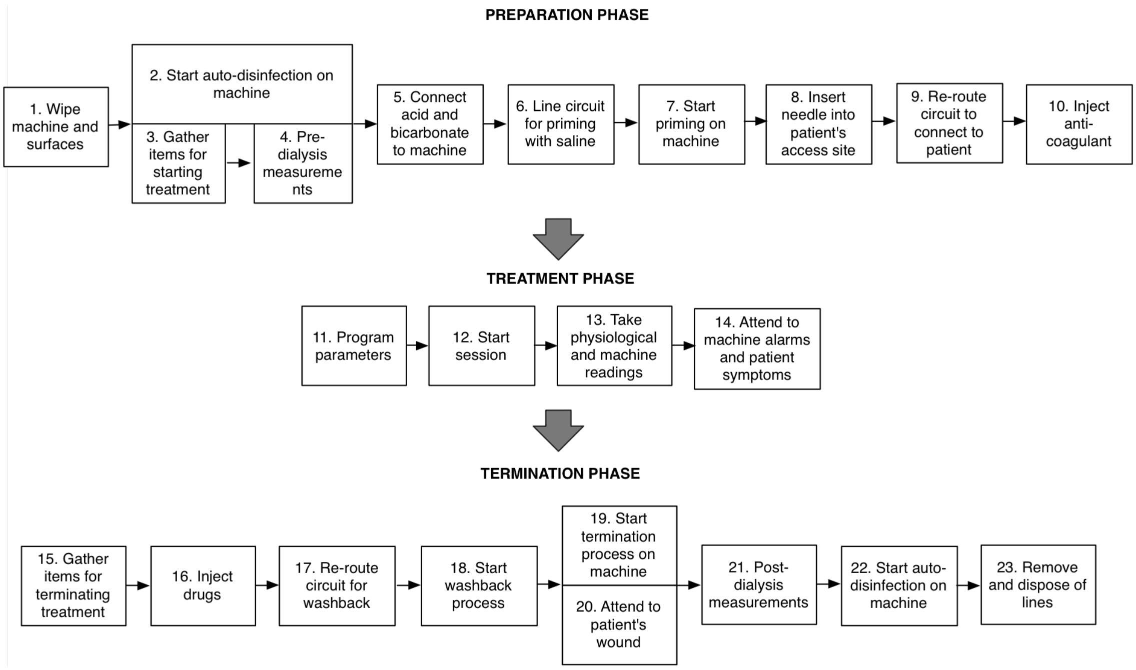


Figure 6.3: Typical temporal layout of tasks within the Dialysis activity

The analyses in the subsequent DiCoT models focus on understanding patients' interaction strategies and issues related to the tasks described above. Here I highlight one particular issue that is not captured in these analyses. Several patients report that needling themselves is the most problematic part of their dialysis activity. E.g. Fiona mentions that the only thing that she finds difficult is the needling, and nothing to do with the machine, in the sense that it is not a nice thing to do and she has to do it four times a week. This points to the potential use of affective technology (Picard, 2000) to help the patient cope with emotions of pain or frustration associated to needling. The needling can also be practically tricky to do, as it can take time for the patient or carer to locate the correct access point, which changes with time, and to find the proper angle of insertion. Future technology could potentially assist the patient with the insertion of the needle, e.g.

by using ultra-sound technology to help locate the vessel for puncture, as with the "portable vein finder" (Becker, 2006). For a patient who is on their own, it is a practically demanding task, as they have to devise a technique for using their free hand to both prick their fistula with the needle and then attend to any ensuing blood spill. Appendix E Table E.3 reports on these 2 issues.

6.5 Summary of this chapter

This model described HH in terms of systems, activities and tasks, and defined the scope of this study for focusing the rest of the DiCoT analysis: the Dialysis activity, within the HHS. It thus fulfilled Methodological Objective 1, of making sense of the complexity of the context of HH. Additionally, the description of the systems, activities, and tasks that constitute HH, and some strategies and issues identified in the analysis, contribute to the empirical objective of understanding the context in which patients interact with HHT and their interaction strategies and issues. For example, it highlighted how the patient experience could potentially be improved if HHT were designed in consideration of the other activities within the HHS and of the broader systems that the patient is part of.

Chapters 7 to 12 each focus on one aspect of the Dialysis activity: information flows, social structures, physical layouts, artefacts, system evolution, and temporal structures, respectively.

Chapter 7: Information Flows

7.1 Introduction

This chapter focuses on how information flows among agents, which include both people and artefacts, during the Dialysis activity, through the Information Flow Model (Furniss & Blandford, 2006). This model describes the information flows among the agents of a system in terms of the communication channels used and of key flow properties. Furniss & Blandford (2006) define three viewpoints for the information flow: a high level input-output view, an agent-based view, and a third view focusing on key flow properties.

The objectives that this chapter addresses are:

- The empirical objective of understanding the context in which patients interact with HHT and their interaction strategies and issues. The analysis in this chapter describes the context of the Dialysis activity in terms of the information flows involved, and presents some related interaction strategies and issues.
- Theoretical Objective 1, of assessing whether a DCog approach can facilitate the understanding of patients' situated interactions with HHT. The analysis in this chapter shows how HH can be usefully viewed as a distributed cognitive system, involving several human and artefactual agents, and that DCog is therefore a useful approach for understanding situated interactions in HH.

The following three sections each focus on one of the viewpoints mentioned above.

7.2 High level input-output view of information flow

The high level input-output view of the information flow briefly describes what is input into the system, the system factors and resources that relate to the processing done by the system, and what the system outputs (Furniss & Blandford, 2006). In the case of the Dialysis activity, the 'input' to the activity is a patient whose blood needs to be cleaned, and the 'output' from the activity is a patient whose blood has been cleaned. The resources used to achieve this are the TS and other artefacts, and human resources that include the patient, the carer, the helper, the nephrologist, the home nurse and the technician. The next section focuses on the flow of information among the agents involved in this activity, which includes actors and technology.

7.3 Agent-based view and communication channels of information flow

The agent-based view focuses on the principal agents within the system and the flows between them, in terms of the properties of the main communication channels used (Furniss & Blandford, 2006).

Figure 7.1 shows a representation of this view for the Dialysis activity. The agents involved are: the patient, the carer, the helper, the nephrologist, the home nurse, the technician, and the TS. The dotted box serves to show the patient, the carer, and the helper as one unit, since the other agents may interact with any one of them. Also, the nephrologist is shown in a lighter shade, as the nephrologist is not directly involved *during* the Dialysis activity. The role of each agent during the Dialysis activity is described in Table 7.1 and then each communication process and the main channels used are described in Table 7.2. The exact roles of the agents and the flow processes vary across the different hospitals of the study; what I present here is an abstraction across them.

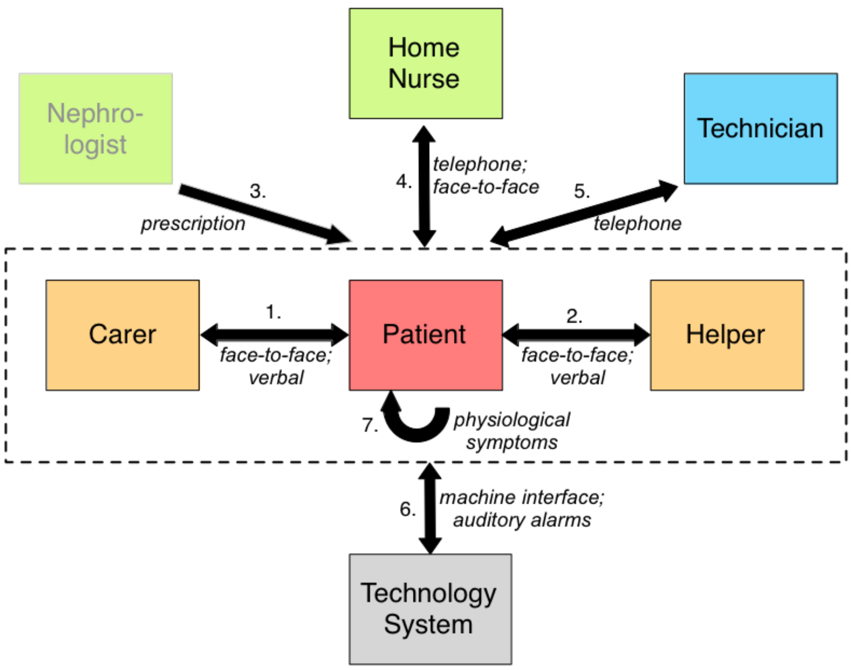


Figure 7.1: Agent-based view of information flow during Dialysis activity, showing communication channels

Table 7.1: Roles of agents involved during the Dialysis activity

AGENT	ROLE
Patient	The patient is the person who receives the dialysis treatment through the machine. A self-caring patient conducts their treatment themselves, including the operation of the dialysis machine.
Carer	A non-self-caring patient has a carer who conducts the treatment for the patient, including the operation of the dialysis machine.
Helper	A patient may have a helper, who helps the patient with some aspects of the treatment, possibly including interactions with the machine.
Nephrologist	The nephrologist sets the dialysis prescription for the patient; the patient programs the dialysis session based on the prescription.
Home Nurse	The home nurse provides support to the patient for patient-related issues and machine-related handling issues that arise during dialysis.
Technician	The technician provides support to the patient for machine-related technical issues that arise during dialysis.
Technology System	The main component of the TS is the dialysis machine, which cleans the patient's blood and removes excess fluids from the patient. Other components include e.g. water purifying units.

Table 7.2: Communication processes during the Dialysis activity and the main channels used

PROCESS	SUMMARY
1. Between Patient and Carer	Communication between the patient and carer may happen while the carer is preparing the patient for treatment, when there are alarms from the machine, or when the patient is suffering from symptoms during dialysis. Communication happens face-to-face (multimodal), or verbally if the carer is in another room.
2. Between Patient and Helper	Communication between the patient and helper may happen when there are alarms from the machine, or when the patient is suffering from symptoms during dialysis. Communication happens face-to-face (multimodal), or verbally if the helper is in another room.
3. From Nephrologist to Patient/Carer	Communication between the nephrologist and the patient/carer that is specific to the Dialysis activity happens indirectly, via the dialysis prescription set by the nephrologist. The patient/carer programs the dialysis session with parameters based on the prescription.
4. Between Patient/Carer/Helper and Home Nurse	Communication between the patient/carer/helper and home nurse, when there is a patient-related or machine-handling related problem during the Dialysis activity, happens by telephone, or face-to-face (multimodal) when the nurse is visiting the patient. If there is a machine-handling problem that the nurse cannot work out on the phone, they ask the patient to abandon that dialysis session.
5. Between Patient/Carer/Helper and Technician	Communication between the patient/carer/helper and the technician, when there is a machine-related technical problem during the Dialysis activity, happens by telephone. The technician will typically ask the patient for the alarm/error code displayed on the machine's screen, and then may look up the error code in a manual. The technician also asks the patient some basic questions and tries to visualize what the patient is doing, and then advises the patient on what to do. If the technician cannot work out what exactly is the problem, but see that there is a chance of the patient being harmed, they ask the patient to clamp the lines and come off the machine, losing the blood that is currently in the circuit.
6. Between Patient/Carer/Helper and Technology System	Communication from the patient/carer/helper to the TS happens via controls on the machine's interface, when e.g. the patient enters the parameters for a dialysis session on the touchscreen. Communication from the TS to the patient/carer/helper happens via the display on the machine's interface, and through auditory alarms and cues.
7. Between Patient and Self	HH patients are typically very sensitive to their physiological state and symptoms, and they react accordingly during dialysis. E.g. one patient is "very in tune with his body", so he can feel it when a hypotensive episode is about to come, and he takes measures for dealing with it. A patient also has to feel for the correct location and angle when inserting a needle into their fistula, based on the sensations of pain or resistance that they feel.

Appendix E Table E.4 reports on 13 interaction strategies and issues related to the communication channels used by agents during the Dialysis activity. Some of the main strategies and issues are presented next. Firstly, several patients introduced an extra communication channel between them and their carer (Process 1), so that they can stay in touch with their carer while their carer is engaged in a HS activity elsewhere in the home, for example on a different floor. Examples of this communication channel are an intercom system from the patient's dialysis site to the kitchen, a pair of walkie-talkies, or a buzzer and alarm set. Figure 7.2 below shows Alex's intercom control. Some patients who do not have this extra channel rely on calling out loud for their carer when there is a problem, e.g. when they suffer from hypotension (see Task 14 in Appendix A Table A.1). This communication channel could potentially be provided by HHT.

Figure 7.2: Alex's intercom control

The second issue is the ambiguity in some cases on whether the nurse or the technician should be contacted for a particular alarm or problem (Processes 4 & 5). When it is clear that the machine has broken down, it is clear that the technician should be contacted, and when it is clear that there is a problem with the patient, e.g. with their fistula, it is clear that the nurse should be contacted. But for some problems, e.g. related to the lining of the circuit or the handling of the machine, it can be trickier for the patient to know whom to contact. The design of the technology can help with this – on M2, a flashing spanner indicates a technical problem whereas a flashing hand indicates a handling, i.e. nurse, problem.

Thirdly, according to some participants, having a communication channel between the DUS and the patient's machine at home would be extremely beneficial. As examples of potential benefits, this could allow: the nephrologist to remotely change the dialysis parameters on the machine, as is often done in satellite units, and to send messages to the patient that are displayed on their machine; the technician to troubleshoot a problem that arises during dialysis more effectively; the nephrologist/nurse to easily retrieve data on the patient's last dialysis sessions; and a patient to dialyse alone at home, with support provided remotely from the DUS. The view of the information flow presented in this section focused on the agents involved and the communication channels used; the next section focuses on information transformation & decision hubs.

7.4 Information Transformation & Decision Hubs in the Dialysis activity

The third view of the Information Flow Model focuses on certain key properties of information flow, and the properties found to be relevant for this study are information transformation & decision hubs (Furniss & Blandford, 2006). Information can be represented in different forms; transformations occur when the representation of information changes (Furniss & Blandford, 2006). In the Dialysis activity, information transformation happens when a patient records pre and post dialysis physiological measurements in their dialysis chart, when they record problems such as unfamiliar alarms in their dialysis chart, and when they record solutions (e.g. from the technician) for problems in their dialysis chart or diary.

Information decision hubs can be considered as a central focus where different information channels meet, and where different information sources are processed together (Furniss & Blandford, 2006). A patient or carer acts as an information decision hub in the Dialysis activity, when they decide on the treatment parameters for a particular dialysis session by considering information from several channels: the nephrologist's prescription, how the patient currently feel in terms of their wellness, and in some cases, the patient's latest blood results on Renal Patient View, a website to which some hospitals upload the patient's results. Godbold (2013) makes a similar remark, and portrays the renal patient as "a potential information locus: potentially able to confirm information such as medical measurements, make measurements themselves, generate information related to their own sensations, and summarise information about the trajectory of their illness." A carer may also act as a decision hub when routinely checking on the patient or when attending to a problem with the patient: they combine information about the patient's physiological state from artefacts such as a blood pressure monitor with information from other channels, e.g. verbally expressed by the patient to the carer, or visually perceived by the carer. One issue related to this is that it can be tricky for the carer to ascertain the current state of the patient, if e.g. the patient is sleeping during dialysis. Once, while Eva was watching television, she fell asleep. Her son saw her sleeping, so he didn't check her blood pressure with the blood pressure monitor for a while, as he didn't want to disturb her. Eventually she woke up feeling very sick, and called her son to give her some fluid.

The technology could help by providing another channel for the carer to get information on the patient's blood pressure, e.g. by automatically measuring the patient's blood pressure during dialysis and displaying it on the interface. Appendix E Table E.5 reports on 4 interaction strategies and issues related to information transformation & decision hubs during the Dialysis activity.

7.5 Summary of this chapter

This model looked at how information flows during the Dialysis activity, helping to understand the context in which patients interact with HHT and to identify their interaction strategies and issues, contributing to the empirical objective. The analysis showed how cognition is distributed in the HH setting in terms of information flows among agents (people and technology). This indicates that DCog is a useful approach for understanding situated interactions in HH, contributing to Theoretical Objective 1. The DCog approach allowed a broad range of interaction strategies and issues to be identified, e.g. it highlighted the safety-critical importance of the communication channel between the patient and the carer. The next chapter looks at the social structures involved in the Dialysis activity.

Chapter 8: Social Structures

8.1 Introduction

This chapter focuses on the social structures involved in the Dialysis activity, through the Social Structures Model of DiCoT (Furniss & Blandford, 2006; Furniss, 2008; Webb, 2008). This model examines how cognition is socially distributed, through shared goal structures and the development and retention of knowledge. These two principles help to understand how systemic social structures influence patients' interactions with HHT. However, as mentioned in Chapter 4, patients' individual knowledge and their values and preferences also influence how they interact with HHT. These are therefore also discussed in this chapter.

The objectives that this chapter addresses are:

- The empirical objective of understanding the context in which patients interact with HHT and their interaction strategies and issues. The analysis in this chapter describes the context of the Dialysis activity in terms of the social structures involved, and presents some interaction strategies and issues related to social structures.
- Theoretical Objective 1, of assessing whether a DCog approach can facilitate the understanding of patients' situated interactions with HHT. The analysis in this chapter shows that cognition is socially distributed in HH, and that DCog is therefore a useful approach for understanding situated interactions in HH. However, it also shows the limits of DCog; some strategies and issues arise from a patient's individual knowledge and their values and preferences, and these are beyond the remit of a typical DCog analysis. These are considered in this chapter, to provide a richer picture of patients' interaction strategies and issues.

The next four sections present the analysis done through the Social Structures Model for the Dialysis activity, in terms of shared goal structures, the development and retention of knowledge, individual knowledge, and values and preferences, respectively.

8.2 Shared Goal Structures in the Dialysis activity

Furniss & Blandford (2006) refer to the description by (Hutchins, 1995) of the way in which a hierarchical structure can map to a goal structure, such that areas of assigned responsibility overlap between superordinate and subordinate to ensure that sub-goals of the overall goal are satisfied. This organisational structure influences the way in which work and responsibility are shared and creates robustness in the system.

In the case of HH, there is no rigid organizational structure, but goals are still shared among actors. Figure 8.1 shows how goals are shared among different actors of the HHS, during the Dialysis activity. The dotted box serves to show the patient, carer and helper as one unit, since the other actors may interact with any one of them in some situations. As above, the nephrologist is shown in a lighter shade, as the nephrologist is not directly involved *during* the Dialysis activity. For the sake of simplicity, the patient is in the centre of Figure 8.1 – in some cases, the carer is the 'main actor', and goals can be shared between the carer and the helper (not shown in Figure 8.1). Table 8.1 describes the shared goals g1 to g6. In this analysis, the focus is on shared goal structures, and therefore patients' more personal goals are not depicted. These personal goals will be touched upon later in Chapter 15, in a reflection on how some patients adopt potentially unsafe strategies to fulfil their goals.

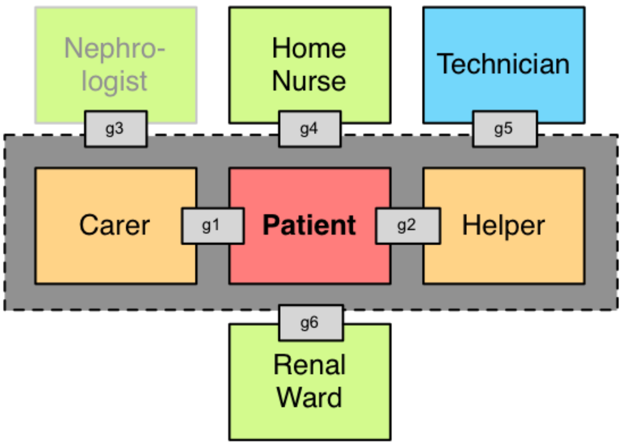


Figure 8.1: Shared goal structures in the Dialysis activity

Table 8.1: Goals shared among actors in the Dialysis activity

GOAL	SUMMARY
g1. Between Patient and Carer	g1 represents goals shared between the patient and the carer, if the patient has a carer. The carer's responsibility can range from fully preparing the patient and the machine for dialysis and being the main person interacting with the machine, to only helping the patient with certain parts of the treatment, such as with the needling or the weekly changing of dressings for a patient with a line access, to only starting the disinfection process on the machine.
g2. Between Patient and Helper	g2 represents goals shared between the patient and the helper, if the patient has a helper. The patient takes the main responsibility of conducting their treatment through the machine, and g2 refers to actions that the helper can also perform, e.g. disinfecting the machine, handing out items, or providing assistance in an emergency.
g3. Between Patient/Carer and Nephrologist	g3 is the high-level goal shared between the nephrologist and the patient to provide HH treatment to the patient. It includes the dialysis prescription that the nephrologist sets for the patient, and the following of this prescription by the patient when programming a dialysis session. The nephrologist adapts the prescription as the needs of the patient change or when the patient experiences symptoms.
g4. Between Patient/Carer/Helper and Home Nurse	g4 represents the goals shared between the home nurse and the patient, which include solving a patient-related or machine-related handling problem during a dialysis session, and advising the patient on what parameters to use when programming the treatment.
g5. Between Patient/Carer/Helper and Technician	g5 represents the goal shared between the patient and the technician, of troubleshooting a problem during a dialysis session.
g6. Between Patient/Carer/Helper and Renal Ward	g6 represents the goal shared between the patient and the renal ward staff, of dealing with a problem that arises during dialysis when the home dialysis unit is closed and the home nurse cannot be reached.

Appendix E Table E.6 reports on 43 interaction strategies and issues related to shared goal structures in the Dialysis activity. Some of the main strategies and issues are discussed next. One main strategy identified is how, when dialysing alone, either because they do not have any carer or helper at all or because their carer is not at home, some patients take measures so they can get help from other people if required. For example, they give their neighbour a spare key to their house, and make sure their phone is next to them during dialysis so they can call their neighbour. For Gina, this proved critical, as once her neighbour came to help her and called an ambulance for her. Alternatively, Bea makes sure she can easily throw the house key to her neighbour through the window if required, as shown in Figure 8.2 below. This highlights an opportunity for technology to help, e.g. by providing support structures through remote monitoring.

Figure 8.2: Bea keeping house key on window sill

In some situations, e.g. when the patient is passing out, the helper, who is not trained on using the machine, may need to intervene and suspend fluid removal on the machine and dispense saline to the patient, to help the patient come round. The design of the machine's interface can help an untrained helper to perform these steps. On M5, pressing a red cross on the display both suspends fluid removal and dispenses a bolus of fluid to the patient, making it straightforward for the helper to intervene. In contrast, on M1, separate actions are required to suspend fluid removal and to dispense fluid to the patient. This can make it trickier for a helper to intervene – once, when Ivan was passing out, Helen struggled to intervene on M1, and eventually was able to perform the steps with the guidance of the home nurse over the phone. This highlights the importance of designing HHT such that people with no training can start emergency procedures.

8.3 Development and Retention of Knowledge for the Dialysis activity

The organisational structure, apart from influencing responsibilities and the sharing of work, as described in the last section, also shapes the way knowledge is developed and retained in the system (Furniss, 2008; Webb, 2008).

Patients develop knowledge on how to conduct their dialysis initially through training at the dialysis unit, and then continue to learn while dialysing at home, from the home nurse, from the technician, and also from their own experiences. The training in the unit lasts from four weeks to several months, depending on the hospital and the time the patient/carer takes to develop the required competencies. These competencies include, e.g. self-cannulation, the handling of the dialysis machine, emergency procedures, and understanding patient symptoms. The initial training in the unit does not cover all possible scenarios in detail, as there is simply too much information, and a patient continues to learn while doing the treatment at home, with the support of the home nurse and of the technician. In the cases of H1 and H4, the nurse visits the patient at home regularly in the beginning. In the early days at home, the patient typically faces teething issues, and tends to phone the home nurse and the technician more frequently, to double-check when they are not sure of a procedure or when they encounter a new problem. As the patient does their treatment at home, they learn new things from their own experiences and they learn the quirks of using the machine. Many patients report making mistakes in the beginning and then learning from these mistakes. These mistakes typically involve missing a step or doing a step incorrectly in the setting up of the dialysis circuit – the machine detects it and alarms until they figure out the problem and rectify it.

Appendix E Table E.7 reports on 24 interaction strategies and issues related to the development and retention of knowledge for the Dialysis activity. Some of the main strategies and issues are discussed next. One strategy is that some patients double-check things with each other, and support each other in the learning process. According to Alice, she has received quite a lot of phone calls from some other patients in their first few weeks of being at home: "They didn't want to ring the nurse, because they didn't want her to think they hadn't been listening to what they had been taught, but just wanted to double check things." Fiona, who was having doubts about her ability to do the treatment at home, visited Gina, and this gave her confidence to go ahead. Some renal patients seem to prefer to consult each other instead of clinicians. This points to the consideration of how HHT could support patient-patient networking to facilitate learning.

One limitation of the training in the DUS is that, for some problematic situations that cannot be replicated in the unit for training purposes, such as air embolism, the patient is provided with written instructions on what to do. However, a few patients report that they find it hard to understand the written instructions without having experienced the situation, and that they would not be confident in dealing with it if it happened. A possible improvement could be the use of some kind of simulation to train patients on these scenarios, or alternatively, HHT could provide contextual information to help patients deal with them, e.g. using video animations. The learning described in this section results in knowledge being developed and retained within the HHS. The next two sections focus on how a patient's individual knowledge and their values and preferences influence their interaction strategies and issues. These are not social phenomena per se, as they pertain to individuals, but are relevant for this chapter in the sense that they focus on more human aspects of the system.

8.4 Individual Knowledge in the Dialysis activity

As they learn, a patient develops individual knowledge on their treatment and on how the TS works. This analysis does not fall under the usual remit of DCog, but for this study, it helps to understand patients' interaction strategies and issues. This knowledge influences the strategies they adopt and possible issues they face, e.g. due to inadequate knowledge, and how they deal with them. It also includes individual mental models that patients use when troubleshooting issues.

Appendix E Table E.8 reports on 9 interaction strategies and issues related to individual knowledge in the Dialysis activity. Some of the main strategies and issues are discussed next. One main strategy identified is how some patients avoid performing some operations for which they feel they lack knowledge. For example, several patients mentioned that they avoid doing 'recirculation', a procedure through which they can pause the dialysis session and disconnect themselves, e.g. to go to fetch something that they need. They find that procedure tricky, and therefore they prefer to make sure that they have everything they might ever need around them before starting, including for example spare supplies. Another example is that Carl, who is not too sure of how to dispense saline to the patient through the machine, does so manually with a syringe. To help improve the patient experience, the interface design of HHT should ideally actively support the patient in building knowledge of how the technology works.

Some benefits of having a strong level of knowledge are illustrated in the strategies of some patients, when for example they devise ways to deal with problems or to optimise on some aspect of their treatment. Beth found out that she could shorten the duration of a dialysis session during the session, and once when she was feeling "rough" she decreased the duration from 4 hours to 3.75 hours to be able to come off the machine earlier. Similarly, Garry discovered that on M3 he could end the session prematurely by setting all the parameters to zero, and he did that on a few occasions when he wanted to finish dialysis earlier.

8.5 Values and Preferences in the Dialysis activity

Some patients' individual values and preferences influence how they interact with HHT. Although this analysis does not fall under the usual remit of DCog, it helps to understand patients' interaction strategies and issues.

Appendix E Table E.9 reports on 3 interaction strategies and issues related to values and preferences in the Dialysis activity. The main strategy is that several patients optimise on peacefulness and comfort. Some ways in which they achieve that are: dialysing in an atypical location that has a nice view to the outside, e.g. their verandah or living room; reducing the volume level of the machine's alarms; and pre-empting alarms by widening the safety limits, e.g. when they anticipate that the venous pressure alarm (see Task 14 in Appendix A Table A.1) may go off soon. This implies that designers of HHT should be sensitised to some patients' preferences for peacefulness and comfort.

8.6 Summary of this chapter

This model focused on understanding the social structures involved in the Dialysis activity, helping to understand the social context in which patients interact with HHT and their related strategies and issues. It thus contributed to the empirical objective. The analysis also demonstrates how cognition is distributed socially in the Dialysis activity, contributing to Theoretical Objective 1. The DCog approach allowed a broad range of interaction strategies and issues to be identified, e.g. it highlighted the need for HHT to be designed such that a helper with limited or no training can easily interact with the technology in case of an emergency. However, DCog has some limitations as a theoretical framework. Some strategies and issues arise because of a patient's individual knowledge or because of their values and preferences, and these are beyond the remit of a typical DCog analysis. On the positive side, DCog is not restrictive and does not strictly preclude other factors from the analysis. A richer picture of patients' interaction strategies and issues was provided by also considering patients' individual knowledge and their values and preferences in this chapter. Cognition can also be distributed through the physical environment, and this is the focus of the next chapter.

Chapter 9: Physical Layouts

9.1 Introduction

This chapter focuses on the physical layouts involved in the Dialysis activity, through the Physical Layout Model of DiCoT (Furniss & Blandford, 2006). This model studies how the physical environment aids actors in their cognitive work, by examining the physical layout, the arrangement of equipment, and through principles such as space and cognition, physical naturalness, situation awareness and horizon of observation. Additionally, some issues related to the physical ergonomics of interacting with HHT are reported in this chapter.

The objectives that this chapter addresses are:

- The empirical objective of understanding the context in which patients interact with HHT and their interaction strategies and issues. The analysis in this chapter describes the context of the Dialysis activity in terms of the physical layouts involved, and presents some interaction strategies and issues related to physical layouts.
- Theoretical Objective 1, of assessing whether a DCog approach can facilitate the understanding of patients' situated interactions with HHT. The analysis in this chapter shows how cognition is distributed through the physical environment in HH, indicating that DCog is a useful approach for understanding situated interactions in HH.

The next six sections present the analysis done through the Physical Layout Model for the Dialysis activity, in terms of the physical layout, the arrangement of equipment, physical ergonomics, space and cognition, physical naturalness, and situation awareness & horizon of observation, respectively.

9.2 Physical Layouts in the Dialysis activity

From a DCog perspective, the physical layout affects communication among actors and access to artefacts (Furniss & Blandford, 2006).

Of the 19 participants in this research, 9 dialyse in a special purpose room, 7 dialyse in their bedroom, 1 dialyses on her verandah, 1 in his living room, and 1 in her husband's home office. The dialysis site is determined mostly by the availability of a spare room in the house, by existing plumbing arrangements, and by the patient's preference. Almost all patients keep all equipment and some supplies in the room where they dialyse, to have everything in one place and facilitate access, but also to protect the aesthetics of the broader HS; in a sense, all the 'clinicalisation' has been done to the room where dialysis is done, so that the rest of the home is spared. As an example of a layout in a special purpose room, Figure 9.1 below shows the physical layout in Alex's dialysis room. From left to right, it shows the machine, the weighing scale (circled), the chair on which he dialyses, and his dialysis chart (circled). Around the room are different dialysis supplies.

Figure 9.1: Physical layout in Alex's dialysis room

The machine and other components of the TS are bulky and take a lot of space, but the intrusiveness of HH is not limited to the dialysis site. A big stock of dialysis and medical supplies needs to be kept at home, as typically stock delivery happens once a month. Most patients have a main stock somewhere else, e.g. in their shed or attic, and then a small stock in the dialysis room or close by; they replenish the small stock from the main stock when needed. The intrusion extends even to the refrigerator in the kitchen, as erythropoietin is kept in it.

Appendix E Table E.10 reports on 10 interaction strategies and issues related to the physical layout in the Dialysis activity. Some of the main strategies and issues are discussed next. Some strategies are to do with the location of the dialysis room with respect to the rest of the home. Some carers, who do not have a special communication channel to their patient, as discussed in Chapter 7, come to the same floor of the dialysis room or to a room nearby at the stage in the treatment when the patient is most likely to feel unwell, so they can be within the verbal communication reach of the patient. In some situations, a few patients had to call out loudly for their carer who was on a different floor of the house when they felt they were passing out, and fortunately their carer heard them and came to help. Jill: "I remember once when I was having problems I did feel I was sort of passing out…I could feel myself going and I called out to my mum...And she heard me, so she came up…" As discussed in Chapter 7, HHT could provide a communication channel between the patient and the carer to make it easier for them to deal with such situations.

Another issue with respect to the physical layout is that most patients and their families see the machine as an intrusion into the HS. Many of them cope with this by having a secluded, special purpose 'hospital room' for dialysis, which they try to avoid going into when they are not dialysing. Some patients attempt to conceal the machine, e.g. Eva keeps her machine in a closet in her bedroom, as shown in Figure 9.2 below. For patients who have no choice but to dialyse in their bedroom, this creates issues due to conflicts with expectations of the bedroom as part of the broader HS. As examples, it causes psychological stress for Kevin, it causes a privacy issue for Gina, as people such as the nurse and the technician need to come to her bedroom, and for some other patients it causes a mess in their bedroom due to the many different items that need to be kept in it, including components of the TS and supplies. This stresses the need to design HHT such that it fits with the aesthetics and activities of the HS. Whilst this principle looked at the physical layout in terms of the location of the dialysis site with respect to the broader HS, the next principle focuses on the arrangement of equipment in the dialysis site.

Figure 9.2: Eva's machine kept in a closet in her bedroom

9.3 Arrangement of Equipment in the Dialysis activity

From a DCog perspective, the arrangement of equipment affects access to information, and hence the possibilities for computation (Furniss & Blandford, 2006).

The layout of equipment in the dialysis site influences access to the main artefacts used by the patient during the Dialysis activity, which are: components of the TS, mainly the dialysis machine; dialysis supplies; medical supplies; equipment (e.g. weighing machine); information artefacts (e.g. dialysis chart); communication tools (e.g. telephone); medications; and entertainment items (e.g. TV). Most participants keep information artefacts, such as lists of emergency telephone numbers, manuals, and instructions, close by, e.g. on a notice board in the room or framed on the machine itself. Figure 9.3 below shows how Fiona framed the list of emergency telephone contacts on her machine. One influence of the HS on the HHS is the way that entertainment items that patients use during dialysis are kept around the dialysis site. E.g. almost all participants have a TV or computer display in front of their bed, and some participants additionally keep books, music players or portable DVD players on or close to the bed.

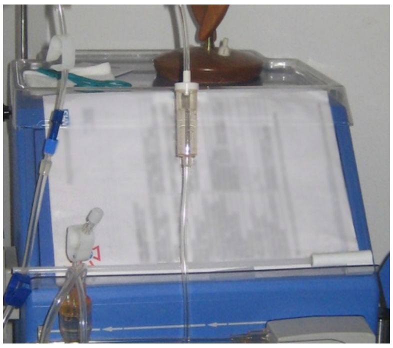


Figure 9.3: An emergency contact list framed on Fiona's machine

Appendix E Table E.11 reports on 16 interaction strategies and issues related to the arrangement of equipment in the Dialysis activity. One issue is how the limitations of the physical environment in which equipment is arranged and manoeuvred in the home, as compared to the dialysis unit, can create new extraordinary situations for patients. E.g. Adam and Cindy reported the acid line getting dislodged from the tank by the arterial line, because the latter was stretched and taut, and because there was a tangle of wires. They struggled a lot to solve the machine's alarm, as they had not been in that situation before. Figure 9.4 shows an example of the arterial line (red with blood) crossing the acid line (transparent, with a white cap) in Adam's arrangement of equipment. One implication of this is that patients should be informed during their training of problems that can arise in the home environment due to kinking and crossing of lines, so they are better prepared to deal with them. The next section focuses on the arrangement of the machine with respect to the position of the patient and other issues related to physical ergonomics.

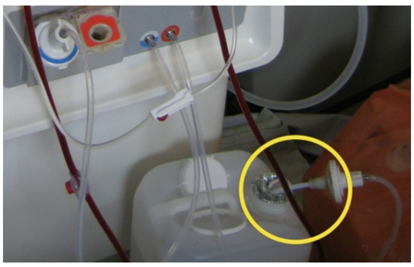


Figure 9.4: Crossing of arterial and acid lines in Adam's arrangement of equipment

9.4 Physical Ergonomics in the Dialysis activity

During the studies, some issues that patients have when physically interacting with HHT were identified. Though this analysis does not fall under the usual remit of DCog, it helps to understand the interaction strategies and issues of patients related to the physical environment.

Appendix E Table E.12 reports on 8 interaction strategies and issues related to physical ergonomics in the Dialysis activity. Some of the main strategies and issues are discussed next. Firstly, several patients have trouble reaching their machine comfortably from their position on their bed or chair. Participants using M2 reported liking that the machine has an extendable arm for easy positioning of the screen, which allows them to reach the interface even while lying down on the bed. Secondly, some patients find the physical buttons and clamps of their machine hard to press. This is worsened during dialysis, as they feel weaker because of the treatment. Thirdly, some patients have difficulty in doing fiddly tasks such as manipulating syringes and supplies. This almost led Jill to accidentally inject air into her dialysis circuit once, while injecting a drug into it with a syringe. Bea gets around her difficulty by using scissors in some tasks, though this is not allowed by the hospital due to infection risks. These issues highlight the need to design HHT with consideration for the physical limitations that some patients may have. The next section looks at how spatial arrangements support cognition in the Dialysis activity.

9.5 Space and Cognition in the Dialysis activity

Furniss & Blandford (2006) refer to the discussion of Hollan et al. (2000) on the role of space in supporting cognition, by supporting choice, problem-solving and planning.

Appendix E Table E.13 reports on 6 interaction strategies and issues related to space and cognition in the Dialysis activity. One strategy is that Adam, who in the past forgot to use the anticoagulant before starting treatment, lays down everything on a table before starting to help him ensure that he uses the anticoagulant – there should be nothing left on the table if he has done all the steps. Figure 9.5 below shows the table that he uses (there are no dialysis items on it as treatment has already started). One issue identified is that the broader HS can interfere with such a strategy. Once some random objects on the table, typical of the home, occluded the anticoagulant, preventing Adam from seeing it, and he forgot to take it. This resulted in blood clotting in the extracorporeal circuit and him having to scrap the lines and start over again. This issue will be re-visited in

Chapter 13, as there are more CFs that need to be considered when reflecting on a design solution for it. Whilst this principle focused on physical representations that are implicit, the next principle, of physical naturalness, focuses on more explicit physical representations.

Figure 9.5: Table area on which Adam lays out dialysis items to remember to inject anti-coagulant

9.6 Physical Naturalness in the Dialysis activity

Furniss & Blandford (2006) refer to the argument of Norman (1995) that cognition is aided when the form of a representation matches the properties of what it represents, as the mental transformations required to make use of the representation are reduced. Some patients rely on elements of machine design that pertain to the principle of naturalness, when setting up the machine for dialysis. E.g. on M1, red and blue lines are drawn on the machine around where the arterial and venous lines need to be fitted, and some patients reported using this as a guide when doing the lining. Some patients also create other physical representations, e.g. Ida marked her fistula access point with a pen, to help her carer know where to insert the needles for dialysis.

One issue reported by Jill, who uses M2, is that, before, the caps on the dialyser for M2 used to be completely blue and red to help distinguish between the arterial and venous ends, but now only very small parts of the caps are coloured, making it harder to distinguish between the two lines. The importance of having clear colour-coding for the different ends of the dialysis circuit is stressed in Allcock et al. (2012), in which the authors report on a fatal incident that happened because a patient wrongly connected the ends of the circuit during the washback phase (see Task 18 in Appendix A Table A.1). Appendix E Table E.14 reports on 6 interaction strategies and issues related to physical naturalness in the Dialysis activity. The next principle focuses on physical elements that help a patient maintain situation awareness during dialysis.

9.7 Situation Awareness & Horizon of Observation in the Dialysis activity

Furniss & Blandford (2006) refer to Norman (1995)'s statement that, in shared tasks, people need to be kept informed of what is going on, what has happened and what is planned; this constitutes situation awareness. They add that the situation awareness of a person is influenced by that person's horizon of observation, which is what that person can see or hear based on their physical location, as discussed by Hutchins (1995).

Appendix E Table E.15 reports on 11 interaction strategies and issues related to situation awareness & horizon of observation in the Dialysis activity. The main strategies are to do with how some participants rely on visual and auditory elements of the physical environment, that are in their horizon of observation, to help them perform certain steps or deal with some situations. An example of a physical element is the visibility of the blood's colour. Once, the unusual blackish colour of the blood indicated to Gina that something was wrong, and she found out later that the anticoagulant that she had used was from a defective batch. This suggests that, though it could possibly be nicer for the patient to not see their blood during treatment, e.g. by having opaque lines, the visibility of the blood can let the patient know of certain problems, and should be retained in the design of HHT.

9.8 Summary of this chapter

This model focused on understanding the physical layouts involved in the Dialysis activity, helping to understand the physical context in which patients interact with HHT and their related strategies and issues. It thus contributed to the empirical objective. The analysis also demonstrates how cognition is distributed physically in the Dialysis activity, contributing to Theoretical Objective 1. The DCog approach allowed a broad range of interaction strategies and issues to be identified, e.g. it highlighted the safety-critical importance of having clear colour-coding in dialysis tubing. Cognition can also be distributed through artefacts present in the physical environment, and this is the focus of the next chapter.

Chapter 10: Artefacts

10.1 Introduction

This chapter focuses on the artefacts involved in the Dialysis activity, through the Artefact Model of DiCoT (Furniss & Blandford, 2006). This model studies how the design, structure and use of artefacts aid actors in their cognitive work, through principles such as the coordination of resources, representation-goal parity, and mediating artefacts.

The objectives that this chapter addresses are:

- The empirical objective of understanding the context in which patients interact with HHT and their interaction strategies and issues. The analysis in this chapter describes the context of the Dialysis activity in terms of the artefacts involved, and presents some interaction strategies and issues related to artefacts.
- Theoretical Objective 1, of assessing whether a DCog approach can facilitate the understanding of patients' situated interactions with HHT. The analysis in this chapter shows that cognition is distributed through artefacts in HH, indicating that DCog is a useful approach for understanding situated interactions in HH.

The next three sections present the analysis completed through the Artefact Model for the Dialysis activity, respectively in terms of the coordination of resources, representation-goal parity, and mediating artefacts.

10.2 Coordination of Resources in the Dialysis activity

Furniss & Blandford (2006) refer to the Resources Model (Wright et al., 2000), in which resources are described as abstract information structures that can be internally and externally coordinated to aid action and cognition. The six resources described are: plan (sequence of goals), goal (current target state in plan), possibility (affordance), history, action-effect, and current state. Coordination of resources implies e.g. coordinating the plan with the current system state to determine the next goal to be achieved.

There are two main aspects to the coordination of resources during the Dialysis activity: the coordination done by the machine, e.g. when it ensures that the patient achieves the correct goal at a particular step; and the coordination done by the patient, e.g. for tasks in the treatment plan that are outside the machine's control. M1 and M5 walk the patient through the procedures for many or most things, helping them learn to perform even some technical operations, for example, changing the filter at the back of the machine. All patients stated that they find it really positive that their machine alerts them in case they have done something wrong or they forgot to do something, and that it will not go any further until the problem is corrected. For example, Cindy feels very confident using the machine because there are a lot of safety features built-in: "if you don't do everything in the set order, the machine will tell you. It is fool-proof and you virtually can't make a mistake with it."

In some situations, the machine does not help with resource coordination, and patients have to coordinate resources themselves. This can be during alarm troubleshooting, which involves the patient internally coordinating resources that represent the state of the system and resources that represent the goal that will fix the problem, or when having to remember to do a step that the machine does not control, which involves the patient internally coordinating a plan resource with state and goal resources. E.g. when there is a low water pressure alarm, on M1 the message displayed is "conductivity low" and the water treatment unit alarms at the same time. Given that, from his experience, the water treatment unit alarms only when there is a low water pressure, Adam coordinates these two resources to know that the alarm on the machine is also due to the low water pressure (the "conductivity low" message by itself is not very meaningful to him). So, after ensuring that the water pressure is normal again, e.g. by asking whoever is using water in the house to stop, Adam just resets the alarms.

Appendix E Table E.16 reports on 31 interaction strategies and issues related to the coordination of resources in the Dialysis activity. Some of the main strategies and issues are discussed next. One prevalent issue when patients have to coordinate resources themselves is that there is a risk of them forgetting to do a particular step or not knowing that a particular step has to be done. E.g. Gina used to forget to change the sodium setting when entering the parameters for a session, until she stuck a reminder on the machine's interface, as shown in Figure 10.1 below. The note says "REM TO SET SODIUM TO 138". This strategy and other strategies for remembering to perform steps will be revisited in more detail in CFA in Chapter 13.

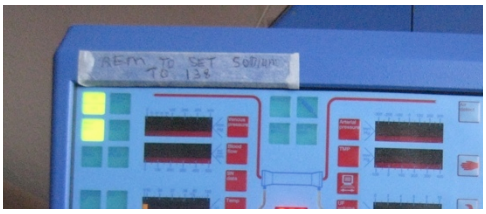


Figure 10.1: Gina's note on her machine to remind her to change the sodium setting

According to Terry, a renal technician, most of the calls the technicians get are due to simple handling problems during lining or priming, when e.g. a patient left a clamp on somewhere or did not connect something properly. In these cases, though the machine points out that something is wrong, the onus is typically on the patient to figure out what exactly is wrong. The interface of HHT should assist the patient in detecting the cause of the problem, e.g. by suggesting possible causes, as is the case with M5.

Another issue is that the coordination of resources done by the machine in some phases of the treatment can be perceived as unnecessary or even annoying. E.g. while Ivan is coming off, he presses a button to start the termination procedure on the machine and then starts taking his needles out. While he is holding the needles and his wound, the machine keeps pinging to go over to the next termination step: "But it keeps pinging saying, look, we've got to go over to the next test now. And that annoys me. I know what I've got to do next, but I can't do anything because I'm attending to my arm, so it's just one of those things…" According to Ivan, his machine is not really designed for the home – in the unit it makes sense for the machine to ping to proceed to the next termination step while the patient is attending to their wound, as there is a nurse who can then interact with the machine, but in the home a patient may be on their own. This highlights the need to design HHT based on likely scenarios of use in the home. The next section focuses on representation-goal parity in the Dialysis activity.

10.3 Representation-Goal Parity in the Dialysis activity

Furniss & Blandford (2006) refer to Hutchins (1995) and describe representation-goal parity as a way in which an external artefact aids cognition by providing an explicit representation of the relationship between the current state and a goal state. The closer the representation is to the cognitive need or goal of the user, the more powerful that representation will be.

Appendix E Table E.17 reports on 6 interaction strategies and issues related to representation-goal parity in the Dialysis activity. An example of a strategy that leverages good representation-goal parity provided by the machine's interface is how, when dealing with arterial and venous pressure alarms (see Task 14 in Appendix A Table A.1), some patients refer to representations on the machine's interface that indicate exactly what the current state of the system is compared to the target state, that is the goal. E.g. when a pressure alarm seems to be due to the position of the needle going into his arm, Adam jiggles the needle while looking at the vertical pressure meter on the machine's interface, which goes up or down real-time, until the pressure gets in the normal area. Figure 10.2 below shows the arterial and venous pressure bars, first and second from the left respectively. For each pressure bar, the two triangular pointers represent the lower and upper pressure limits. This strategy illustrates how patients make use of a good design feature to help them deal with a situation.

Figure 10.2: Pressure bars with lower and upper limits (triangular pointers) on the interface of M1

One common issue is that, in some cases, even though the machine coordinates resources and attempts to tell the patient what the problem is, the machine's message is not always understandable by the patient or does not adequately guide the patient on the course of action. In other words, the interface provides poor representation-goal parity. E.g. once Adam struggled with a particular alarm he had never encountered before. After spending some time analysing the setup of the machine, he realized that the bicarbonate probe had got dislodged from the canister. Though the solution was simple, that is just putting the probe back into the canister, the message displayed by the machine did not point towards it.

Wherever possible, the interface of HHT should provide meaningful messages to the patient that clearly indicate what the problem is in simple terms, and ideally suggest possible solutions. The resources that need to be coordinated, especially plan and goal resources, can be represented through other artefacts. The next section focuses on such mediating artefacts.

10.4 Mediating Artefacts in the Dialysis activity

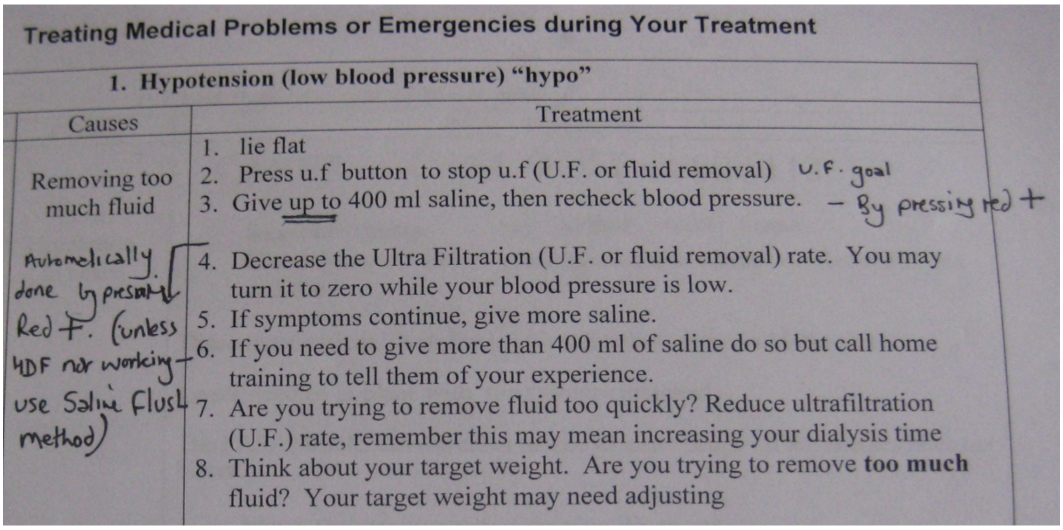
Furniss & Blandford (2006) refer to mediating artefacts, as termed by Hutchins (1995), and describe them as including any artefacts that are brought into coordination in the completion of a task.

Patients use a number of mediating artefacts in the Dialysis activity. The main ones are their dialysis chart, their prescription, manuals/booklets with default instructions on procedures, and other artefacts such as emergency contact lists and speed-dial telephone numbers. The dialysis chart serves the main function of recording the patient's physiological readings and readings from the machine, so the nurse can assess the treatment of the patient. The prescription from the nephrologist specifies the parameter values that the patient needs to use when programming their treatment, and how the patient can vary the value depending on the situation, e.g. increasing the temperature of the dialysate from 35.5 to 36 degrees Celsius if they are feeling cold. The machine manual provides instructions for tasks involving the machine, and booklets from the hospital provide instructions for other tasks. Many patients have emergency contact lists close to their dialysis site, and some have phone numbers, e.g. of their neighbour/friend, saved on speed-dial on their mobile phones.

Appendix E Table E.18 reports on 18 interaction strategies and issues related to mediating artefacts in the Dialysis activity. Some of the main strategies and issues are discussed next. Some patients create and use mediating artefacts that represent plan and goal resources. As an example of a user-created artefact, to allow his mother, Heidi, to turn on the machine and start the disinfection process, Carl put a set of stickers on the machine's touchscreen. These stickers, in the form of red dots, shown in Figure 10.3 below, indicate to Heidi which buttons she needs to press: 1) press "On"; 2) press "Function"; 3) press "Disinfect" (not shown in Figure 10.3); and 4) press "Prim-ven" [Prime Venous]. The disinfection takes about 50 minutes, and by getting Heidi to start it while he is driving to his parents' place, Carl saves considerable time. This strategy illustrates an externalisation of a plan and again highlights how people who are untrained on using the machine may interact with it. To better fit in the context of use, HHT should be designed such that lay people can easily interact with it in case of emergency, as discussed before, but also for initialisation tasks such as the disinfection.

Figure 10.3: Four red stickers placed by Carl to guide Heidi to turn on the machine and start the disinfection.

Some patients also adapt existing artefacts based on their experiences, so that these are more effective or better suit their needs or preferences. As an example of augmenting a default artefact, several patients add notes to the instruction booklets they received from the hospital. Based on their experiences, they add more detail or clarifications to the instructions. Figure 10.4 below shows some notes that Jim added to the default instructions for dealing with hypotension. These notes describe how step 3 is achieved with the specific machine that he uses: "by pressing red +" (on right edge). This highlights the importance of such artefacts being in a tailorable form, so that patients can tailor them to their own situation or augment them to improve their usefulness.



Treating Medical Problems or Emergencies during Your Treatment

1. Hypotension (low blood pressure) "hypo"	
Causes	Treatment
Removing too much fluid	1. lie flat 2. Press u.f button to stop u.f (U.F. or fluid removal) U.F. goal 3. Give up to 400 ml saline, then recheck blood pressure. – By pressing red +
Automatically done by pressing Red +. (unless HDF not working – use Saline Flush method)	4. Decrease the Ultra Filtration (U.F. or fluid removal) rate. You may turn it to zero while your blood pressure is low. 5. If symptoms continue, give more saline. 6. If you need to give more than 400 ml of saline do so but call home training to tell them of your experience. 7. Are you trying to remove fluid too quickly? Reduce ultrafiltration (U.F.) rate, remember this may mean increasing your dialysis time 8. Think about your target weight. Are you trying to remove **too much** fluid? Your target weight may need adjusting

Figure 10.4: Notes added by Jim to the default instructions from the hospital

10.5 Summary of this chapter

This model contributed to the empirical objective of understanding the context in which patients interact with HHT and their related strategies and issues, by focusing on the artefacts involved in the Dialysis activity. The analysis also contributes to Theoretical Objective 1, by demonstrating that cognition is distributed through artefacts in the Dialysis activity. The DCog approach allowed a broad range of interaction strategies and issues to be identified, e.g. it highlighted the need for representations provided by the interface of HHT to be more meaningful to patients. Cognition can also be distributed through time, in the sense of system evolution, and this is the focus of the next chapter.

Chapter 11: System Evolution

11.1 Introduction

This chapter focuses on the evolution of the Dialysis activity, through the Evolutionary Model of DiCoT (Furniss & Blandford, 2006; Furniss, 2008; Webb, 2008). This model studies how the system evolves over time, in terms of how practice develops, through cultural heritage, and how practitioners develop, through expert coupling.

The objectives that this chapter addresses are:

- The empirical objective of understanding the context in which patients interact with HHT and their interaction strategies and issues. The analysis in this chapter describes the context of the Dialysis activity in terms of the development of practice and of the development of practitioners over time, and presents some interaction strategies and issues related to these.
- Theoretical Objective 1, of assessing whether a DCog approach can facilitate the understanding of patients' situated interactions with HHT. The analysis in this chapter shows that cognition is distributed through time, in the sense of system evolution, in HH, and indicates that DCog is a useful approach for understanding situated interactions in HH.

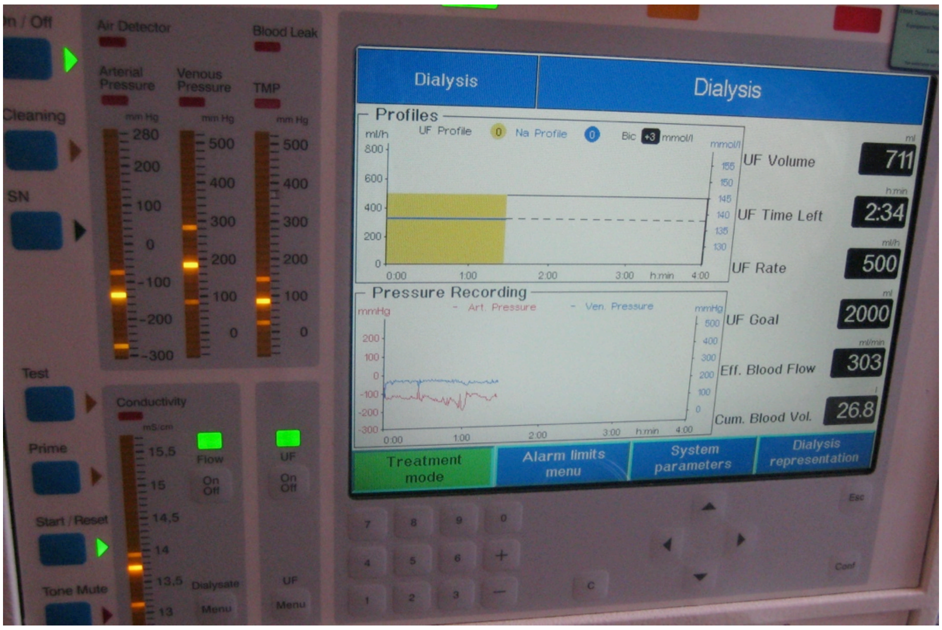
The next two sections present the analysis done through the Evolutionary Model for the Dialysis activity, respectively in terms of cultural heritage and expert coupling.

11.2 Cultural Heritage in the Dialysis activity

Furniss & Blandford (2006) refer to Hutchins' (1995) argument that people have been left with an enriched landscape to support their behaviour; this constitutes cultural heritage. Hutchins refers to Simon's (1981) parable of an ant's movements on a beach, randomly looking for food. Eventually, other ants go straight to the food. This happens because previous ants change the landscape of the beach by leaving chemical trails that guide subsequent ants directly to the food. In the same way, people are left with a cultural heritage that supports them in their activity.

HH evolves over time, all over the world, but also in a specific country, or even in a specific hospital; in this way, future patients benefit from a better experience of

HH. Beth, who has been dialysing for more than three decades and has used several types of haemodialysis technologies, notes how the patient experience has greatly improved over time, as the technology has evolved. Terry, who has been a renal technician for three decades, notes how the safety of haemodialysis has drastically improved over the years. The patient experience improves as the hospital refines its practices for doing dialysis treatment and as technology manufacturers refine the design of the technology, based on the experiences of previous patients. As an example of a refinement in practice, H1 recently introduced a supplementary checklist into their training content, to cover additional topics such as extra precautions necessary when dialysing in the home as compared to the unit, and potential adverse drug reactions. As an example of a refinement in technology design, M5, the successor of M4, walks the patient step-by-step through some tasks. Figure 11.1 below shows the interface of M4 at the top, consisting of physical buttons, and the interface of M5 at the bottom, consisting of a touchscreen.



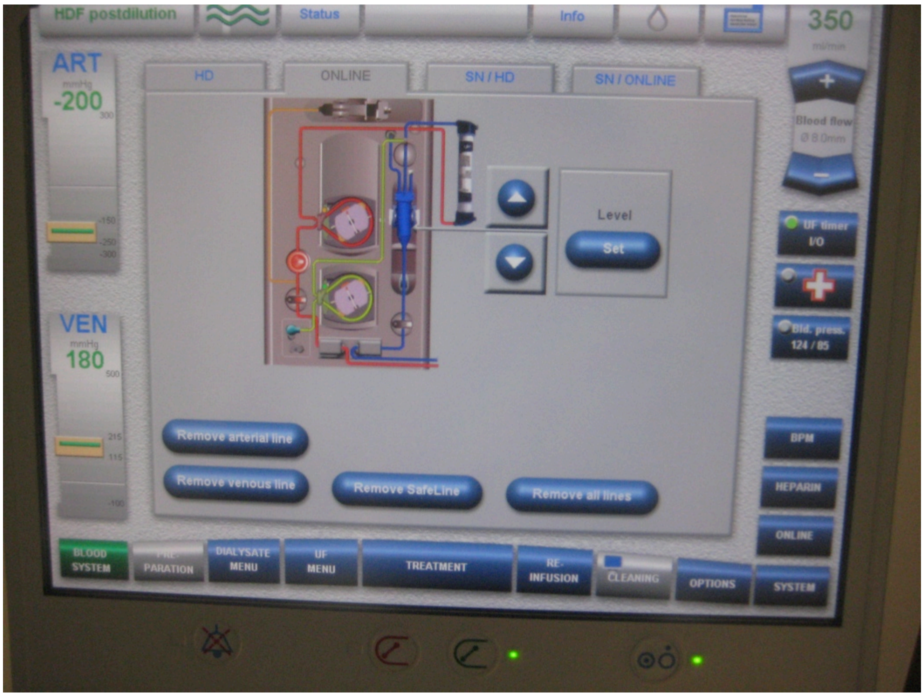


Figure 11.1: Interfaces of M4 (top) and M5 (bottom)

One strategy related to cultural heritage is that one of the reasons why Jim chose to dialyse in his living room, as opposed to a secluded ‘hospital room’, is so that his children can start becoming familiar with the treatment. His rationale is that, since some kidney diseases are hereditary, there is a chance that his children may have to do the treatment as well one day. This serves as an exception that, though many patients prefer to conceal their treatment from the rest of the home, a patient may want to expose the rest of the home to their treatment.

One issue related to cultural heritage is that some HH machines seem more to be repurposed versions of machines designed for use in clinical settings, than machines designed for home use 'from scratch'. Indeed, Gupta (2007) remarks that many HMDs have the same technologies as their professional versions, and are simply scaled down versions of their professional types. Consequently, a home machine may 'inherit' design features that are meant for the dialysis unit, but are problematic for self-care at home. An example of this is reflected in the issue faced by Ivan, discussed previously in Chapter 10: in the treatment termination phase, while he is holding the needles and his wound after disconnecting from the circuit, the machine keeps pinging to go over to the next termination step. This design makes sense in the dialysis unit, as there is a nurse who can interact with the machine while the patient is attending to their wound, but not necessarily in the home, as a patient may be on their own. Appendix E Table E.19 reports on 5 interaction strategies and issues related to cultural heritage in the Dialysis activity.

11.3 Expert Coupling in the Dialysis activity

Furniss & Blandford (2006) refer to the argument of Hollan et al. (2000) that as a user gains experience, they become tightly coupled with the environment of a system and perform better in it. It was found that, as patients learn with time, some become experts in their treatment and in the use of HHT. They develop a strong level of knowledge and confidence, that seems to surpass that of hospital staff members in some aspects, and they understand the nuances of using their machine. This is reflected in how they react to some alarms – their reactions are swift, or even pre-emptive, as they are closely coupled with the environment. One implication discussed previously is that HHT could support patient-patient networking to facilitate learning and knowledge exchange – this could effectively leverage the knowledge of expert patients.

Appendix E Table E.20 reports on 7 interaction strategies and issues related to expert coupling in the Dialysis activity. One strategy is that several long-time patients choose to dialyse on the weekend, even though support from the DUS is not available. Additionally, some choose to sleep while they are dialysing, or sometimes even to dialyse at night while they are asleep. In contrast, newer patients avoid dialysing during the weekend, do not dialyse at night, and do not sleep during dialysis, in case some problem happens. This resonates with the findings of Cafazzo et al. (2009); two of the patient-perceived barriers to the adoption of nocturnal HH that they found were fear of a catastrophic event in the absence of nursing support, and lack of self-efficacy.

11.4 Summary of this chapter

This model focused on understanding the evolution of the Dialysis activity, helping to understand the context in which patients interact with HHT and their related strategies and issues, thus contributing to the empirical objective. The analysis also demonstrates that cognition is distributed through time, in the sense of system evolution, in the Dialysis activity, contributing to Theoretical Objective 1. The DCog approach allowed a number of interaction strategies and issues to be identified, e.g. it highlighted how expert patients dialyse even when support is not available from the DUS, or while sleeping. Cognition can also be distributed through time in the sense of short-term temporal structures supporting activity, and this is the focus of the next chapter.

Chapter 12: Temporal Structures

12.1 Introduction

This chapter presents a new model developed in this research, which focuses on temporal structures. It is different from the previous chapters in that it derives new principles, for understanding cognitive processes distributed through time. It develops these principles by viewing the time continuum as an external medium that can support cognitive processes, analogous to the physical environment. This new model studies how actors use the time continuum to support their cognitive work in immediate activity and reduce complexity in it, through the following principles: temporal layouts, temporal assignments to tasks, dealing with anticipated problems, distribution of a task plan, reducing peak complexity, and time for action. The development of this model constitutes the fourth contribution of this thesis.

The objectives that this chapter addresses are:

- The empirical objective of understanding the context in which patients interact with HHT and their interaction strategies and issues. The analysis in this chapter describes the temporal context of the Dialysis activity, and presents some related interaction strategies and issues.
- Theoretical Objective 1, of assessing whether a DCog approach can facilitate the understanding of patients' situated interactions with HHT. The analysis in this chapter shows that cognition is distributed through time in immediate activity in HH, and indicates that DCog is a useful approach for understanding situated interactions in HH.
- Theoretical Objective 2, of developing principles for the temporal distribution of cognition. Six principles for the temporal distribution of cognition are presented in this chapter.

The next two sections summarise the existing perspectives on temporality in the DCog literature and present a new perspective, that of the time continuum as an external medium that can be used to support immediate activity. Then, sections 12.4-12.9 each presents a principle that builds on this new perspective: temporal layouts; temporal assignments to tasks; dealing with anticipated problems; distribution of a task plan; reducing peak complexity; and time for action. Finally, section 12.10 discusses this new perspective on the temporal distribution of cognition.

12.2 Temporality in the existing DCog literature

Temporality is referred to in two ways in the existing DCog literature: peripherally, when DCog researchers refer to ordinary notions of temporality, and centrally, as a form of DCog.

Temporality is referred to peripherally:

- as a dimension that helps to determine the boundaries of a DCog analysis, as in the ‘‘temporal extent’’ of a phone call (Halverson, 2002);
- as a scale that provides different ‘‘temporal resolutions’’ through which activity can be considered (Kirsh, 1999);
- as a limited resource that constrains the conduct of activity, in the sense of the ‘‘temporal constraints’’ of a system (Hazlehurst, McMullen & Gorman, 2007; Hollan & Hutchins, 2010);
- as a dimension that allows the prediction of the effects of a change in a system, in the context of a system simulation (Kirsh, 2006);
- in the sense of a ‘‘temporal boundary’’ that affects workspace awareness in distributed collaboration (Gutwin & Greenberg, 2004);
- as an element that determines how close members of a globally distributed collaborative group are to the group because of time zone differences, as in ‘‘temporal peripheralities’’ (Hildreth, Kimble & Wright, 2000);
- as a dimension that allows synchronization in activity, as in ‘‘temporal coordination’’ (Kirsh, 2006);
- as a resource that needs to be managed by actors of a system, as in ‘‘temporal reasoning’’ in the context of schedule management (Nemeth & Cook, 2004);
- as a dimension for analysing patterns of behaviour, in the sense of patterns in larger time scales being created by and forming the context for patterns at shorter time scales (Hollan & Hutchins, 2010);
- as in ‘‘temporal limits’’ on human learning, that is, how much can be learned per unit time (Glenberg, 2006);

- and as in a ‘‘temporal distance’’ that represents how far back in the past a decision was made, in the context of collaborative work (Fischer et al., 2004).

Temporality is referred to centrally, that is as a form of DCog, in terms of evolution that happens in a system over time:

1. when current practitioners leverage tools and knowledge developed in the past (Hutchins, 2001);
2. when practitioners become tightly coupled with the environment of a system and perform better in it (Hollan et al., 2000);
3. when people learn in order to act differently in the future, especially when the learning is passed on from generation to generation, or from teacher to teacher (Oatley, 2000).

Temporal distribution of cognition is also referred to in terms of a cultural-historical theory of mind:

4. when parents make the comment ‘‘it can’t play rugby’’ upon seeing that their newborn baby is a girl (Cole & Engestroem, 1993).

In the context of socio-technical systems, the temporal distribution of cognition has been presented in terms of the socio-cultural evolution of a system over time. This perspective was the focus of the previous chapter.

In this chapter, I put forward a new perspective on temporal distribution of cognition; that of time as an external medium that can be used to reduce complexity in cognitive work during short-term activity. As discussed earlier in Chapter 4, some strategies identified in this research involve styles of temporal distribution of cognition that are different from those described in the literature.

12.3 A fresh perspective on time as a medium of distributed cognition

In this research, examples were found of cognition being distributed through time in the sense described in the existing literature, that is of long-term system evolution. These were discussed in Chapter 11. However, besides supporting distributed cognition through long-term system evolution, time, like people, artefacts, and the physical environment, is a medium that can be used to support cognitive work in short-term activity. As a simple everyday example, imagine we are assigned three different tasks. One thing we typically do, to stop having to deal with the question of when we are going to do these different tasks, is to just mentally slot these tasks into, for example, different days of the week, as if putting placeholders for the tasks in a mental calendar. This gives us some sense of relief, as if some 'load' had been taken off of us. Part of this distribution is internal and dependent on us, that is, which task will be done on which day; part of it is external to us, that is, the days of the week are independent of us and can act as cues for tasks we need to do.

It can be elusive to think of the time continuum as an external medium since, unlike the other three media, it does not exist materially and we cannot see it, though we can see its effect on the material world, for example, the day/night cycle. Therefore, I first briefly review how physical structures are used to support cognition, and then I draw some parallels between how temporal structures and physical structures support cognitive work. Among the principles in the literature that describe how physical structures support cognition, some involve creating or using an external representation in the physical environment that bears some meaning to an actor: for example, placing an object somewhere in the physical environment to serve as a reminder or creating a special arrangement to simplify choice (Kirsh 1995). Some principles involve arranging the layout in the physical environment to facilitate access to representations: for example, Kirsh (1995) discusses spatial arrangements that support perception, and Hutchins (1995) discusses the arrangement of equipment to facilitate people's access to physical representations. Principles that directly involve the creation or use of external representations and principles that facilitate access to representations both support cognitive work, and hence are considered within the remit of DCog in the literature. The temporal principles presented below involve the use of external representations, or facilitate the correct execution of task plans, which may be internal representations, or simplify the work that has to be done, or reduce cognitive load around a time of peak complexity. Hence, they point to time as an external medium that can support cognition in immediate activity, compared to time supporting cognition through long-term system evolution.

12.4 Temporal Layouts

This principle simply first gives an overview of a typical temporal layout of tasks; subsequent principles focus on how an actor can arrange the order, duration, and spacing of tasks in the time continuum to reduce complexity in their activity.

Figure 12.1 below shows a typical example of how the tasks in the Dialysis activity are laid out temporally, through three phases of the activity: preparation, treatment, and termination. Boxes that are clustered indicate concurrent tasks. For some patients more tasks can happen in parallel, e.g. as tasks are shared between themselves and their carer/helper.

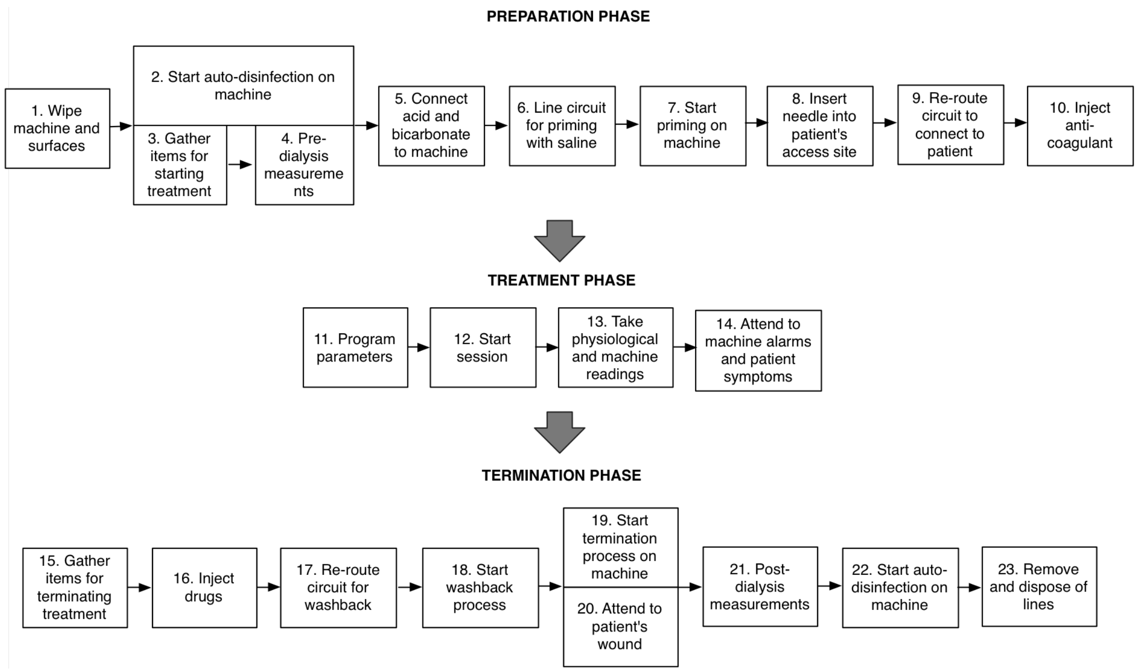


Figure 12.1: Typical temporal layout of the tasks in the Dialysis activity

Participants dialyse at different times of the day, ranging from early morning to evening, and even overnight. The time of dialysis is mostly influenced by the patient's personal preference, and the carer's availability, if applicable. Most participants highlighted that one of the major benefits of HH compared to unit dialysis is that they can dialyse whenever it is convenient for them; they plan their dialysis so as to accommodate activities of the other systems. Many participants also interleave the tasks of the Dialysis activity in which they need to wait for the machine to do something, e.g. the disinfection (Task 2) or the priming of the circuit (Task 7), with activities of the HS, e.g. showering or having breakfast.

The 'treatment regime' varies from patient to patient, and can vary from 3 times a week for 4 hours to daily for 2.5 hours. It depends on the type of machine the patient is using, how much dialysis they need based on the state of their disease, and how they currently feel in terms of their wellness. The duration of the Dialysis activity also varies, depending on the machine being used and the patient's regime. It is typically about 6 hours, including one hour for the preparation phase, four hours for the treatment phase, and one hour for the termination phase.

Appendix E Table E.21 reports on 9 interaction strategies and issues related to temporal layouts in the Dialysis activity. One of the main strategies is that, because they feel the Dialysis activity takes a lot of their time, many patients try to get their treatment done in as little time as possible. For example, they may do the lining of the machine (Task 6) while the machine is disinfecting (Task 2), though they are not taught to do so at the unit. Or, when they are on their way home to dialyse, they may ask their carer/helper to already start the disinfection of the machine. This strategy together with some other strategies for optimising on time will be revisited in more detail in CFA in Chapter 13.

12.5 Temporal Assignments to Tasks

This principle involves an actor assigning a particular time or day to a task and then that time or day serving as a cue to remind the actor of that task. The most common form of this is temporal routines, in which an actor assigns a task to a time or day on a repeat basis.

Renal patients adopt certain temporal routines to help them in remembering to do tasks. These temporal routines can be seen as involving actors putting placeholders in an imagined time continuum. For example, many participants do the special disinfection tasks, which need to be done either once a week or once a month (depending on the machine), on the same day every week, for example, every Tuesday, or on the same day every month, for example, every first Sunday of the month. They assign that day to that task so that they do not forget to do it, at least in principle. In a similar sense, Palen & Aaløkke (2006), in their study of elderly people's management of medication in the home, refer to routines as ''the means by which people recall or at least infer'' that they probably performed a particular task. Besides putting a placeholder in the time continuum for a particular task, as in the above example, another type of temporally distributed cognition is associating a task to be remembered with another task that has an established temporal routine. For example, some participants associate the task of taking their medication with breakfast – a task that already has a solidly established temporal routine. Palen & Aaløkke (2006) also found that elderly people rely on ''temporal cues'' such as mealtimes to remember to take their medication.

A common example of physical distribution of cognition is placing an object at a certain place in the physical environment, such that, when one sees that object, one is reminded of an action that involves that object. An example from this study is a particular patient positioning his anticoagulant bottle on a table next to his machine, so that, on seeing the anticoagulant bottle, he remembers to inject anticoagulant into the dialysis circuit before starting his treatment. A more common everyday example is someone placing a bag at their door to be reminded of taking the bag with them when they leave the house. In this physical distribution of cognition, there is a representation that exists in the external medium, which, in the latter case, is the physical position of the bag in the room. And there is some information that the actor associates with that representation which, in the latter case, is that the bag should be taken when the actor leaves the room. This information resides in the actor's head.

Similarly, when an actor, such as the haemodialysis patient, needs to remember to do a particular task once a week, and the actor copes with this by assigning that task to a specific day of the week on a repeat basis, there is an external representation involved and internal information associated with that representation. The external representation is that particular day of the week, which is a position in the time continuum, for example 'Tuesday'. Note that it is external to and independent of the actor, since time marches on, and the week cycle repeats itself, even if an actor loses track of time. The week is in fact a socio-temporal construct (Palen, 1998), but for simplicity, I treat it as a temporal construct in this discussion. The information associated with that representation, 'Tuesday,' is the task(s) that needs to be done on that day. We can think of this as the actor putting a placeholder box on an imagined time continuum – where the actor puts the placeholder is the day of the week on which the task needs to be done, and the contents of the placeholder are the task(s) to be done on that day. This is illustrated in Figure 12.2 below. The actor may forget about this placeholder box completely, in which case they forget they had to do a task, or the actor may remember that there is a placeholder box, but forget its contents—the familiar scenario when we remember we were supposed to do a task, but we forget what task it was.

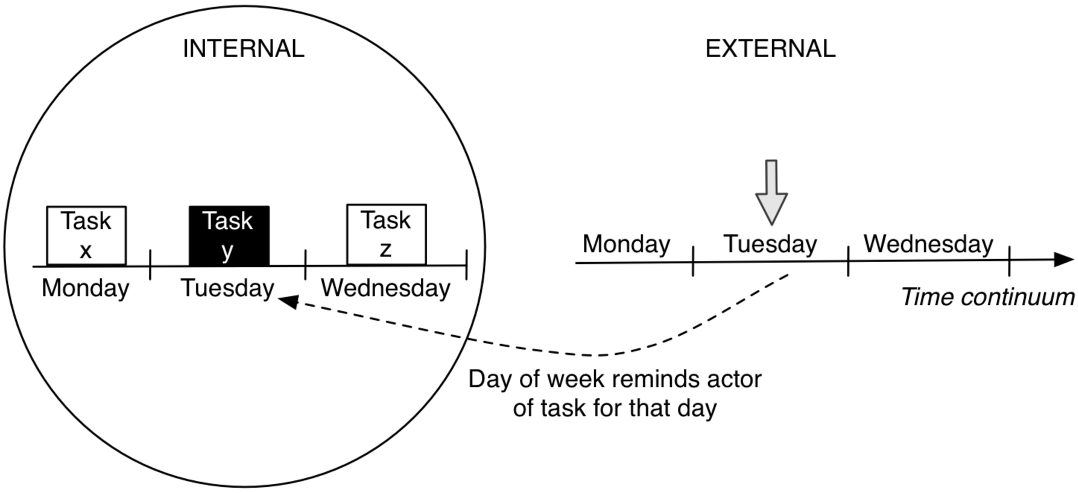


Figure 12.2: Time continuum acting as external representation that reminds actor of task

In the case of a temporal representation acting as a reminder, both the representation and the information associated with the representation do not exist materially by default, whereas a physical representation acting as a reminder exists materially and will also be visible to others, though the associated information may not be known by others. Therefore, it may be easier for an actor to forget a temporal reminder, unless the representation is reinforced through another medium, for example by marking it on a calendar, as done by some participants. This is illustrated in Figure 12.3 below. Ida has to take iron during dialysis every 2 weeks. She has a routine of keeping this task on a Tuesday, but additionally, marks the Tuesdays when she needs to take it on a calendar. Arguably, the fact that it needs to be repeated every 2 weeks instead of every week may make it trickier to rely only on the time continuum as a reminder. Tuesday 3rd and Tuesday 17th are labelled with ‘‘Iron’’ on the calendar.

Figure 12.3: Ida's calendar showing the temporal routines of some tasks

Jim prepares his own custom calendar with all the tasks he needs to do, as shown in Figure 12.4 below. Note the different routines: the injection of Aranesp happens every alternate Friday; the injection of Iron happens every Monday; the injection of Calcidol happens every Monday, Wednesday, and Friday; and the injection of Cabergoline happens every Monday and Friday.

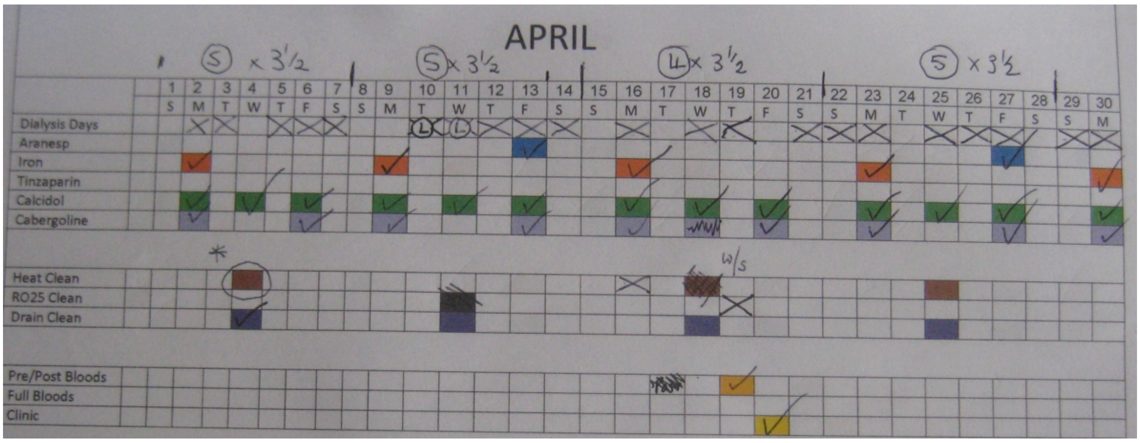


Figure 12.4: Jim's custom calendar showing the temporal routines of all tasks

In contrast, as described earlier, some patients rely only on the time continuum itself serving as a representation to remind them of certain tasks. Appendix E Table E.22 reports on 8 interaction strategies and issues related to temporal assignments to tasks in the Dialysis activity.

12.6 Dealing with Anticipated Problems

In some strategies, participants arrange tasks in the time continuum so that they can more easily deal with potential problems. One form of this principle is performing a task at a certain point to simplify choice among different courses of action in case a particular problem happens later on. This is similar to Hutchins's (1995) observation of how precomputations in the context of navigation ''transform the tasks performed''; the precomputations create new structures that change the cognitive nature of the tasks that must be done in the time-limited performance of the main task. One example of this is the way Carl prepares to deal with eventual symptoms of his patient who, besides suffering from kidney failure, also suffers from diabetes. Some symptoms of low blood pressure, which is a common side effect of dialysis treatment, may appear similar to symptoms of low blood sugar level. To distinguish between the two, Carl measures the Bob's blood sugar level half an hour before dialysis. If the blood sugar level is normal, then, if later on during dialysis the patient does not feel well, Carl knows that it is most likely due to a drop in blood pressure. Then, he can quickly take measures appropriate for dealing with low blood pressure. Thus, the earlier task he performed, that is, measuring the patient's blood sugar level, simplifies the course of action he needs to take if a particular problem happens, that is, if the patient shows symptoms. This is illustrated in Figure 12.5 below.

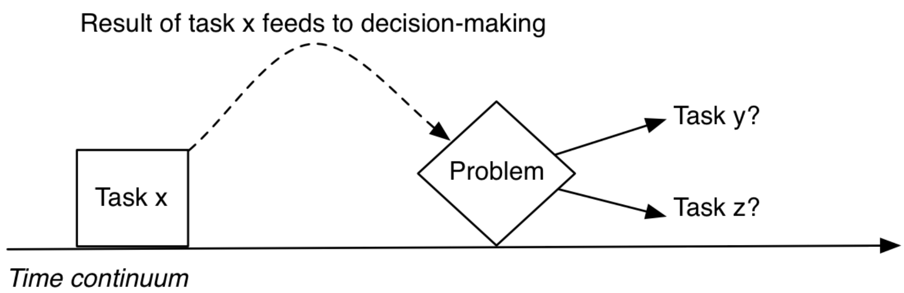


Figure 12.5: Earlier task simplifying choice among courses of action if a problem happens

One way in which physical structures support cognition is through special spatial arrangements that simplify choice, by reducing internal computation that an actor has to do (Kirsh, 1995). Objects are laid out in the physical world such that the object that the actor needs to interact with at a particular point in time is obvious to the actor. Similarly, an actor may arrange their actions in the time continuum such that choice during activity is facilitated, as shown in the example of the carer who measures the patient's blood sugar level in advance.

A second form of this principle is doing a task that has a chance of failure well in advance to allow time for another attempt at the task. An example is the way some participants who use M3 deal with a problem that it has. It requires the patient to prepare a batch of ultra-purified water before the dialysis session. The preparation of this batch takes several hours, and sometimes eventually fails, due to a problem with the sensitivity of the machine. To cope with this, some participants already start the preparation of the batch at night if they want to dialyze on the next afternoon; if the batch failed, they would have time for another attempt on the next morning.

A third form of the principle is an actor performing a task early on in anticipation of a decline in their cognitive resources. If Fiona will be going out with her friends on an evening on which she was planning to dialyze, she may already do some steps in the preparation of the machine before going out, instead of when she is back home from the night. This is because when she comes back, she may be too tired, and unable to properly concentrate on the task and deal with alarms that occur due to mistakes she might make. Appendix E Table E.23 reports on 4 interaction strategies and issues related to dealing with anticipated problems in the Dialysis activity.

12.7 Distribution of a Task Plan

Wright et al. (2000) discuss a task plan as a resource for action, which can exist as an internal representation in an actor's head or as an external representation.

Some participants deliberately do a particular task over more time, effectively allowing more time for executing an internal plan they have, so that the chances of missing out a step in the plan are less. For example, Carl used to start getting ready for taking Bob off the machine only 5 minutes before the end of the treatment. But, since, on some occasions he forgot to get certain items while rushing, now he does it 20 minutes before. By doing the task of preparing the take-off tray over more time, he reduces the likelihood of missing an item. This principle can also be observed in everyday life. For example, when doing the packing for going on a trip, we are less likely to forget some items if we do the packing in a leisurely way than if we do it in a rush.

Physical distribution of cognition may involve arranging the layout in the physical environment such that actors can easily access or perceive representations in that environment (Hutchins 1995; Kirsh 1995). Similarly, when an actor decides to increase the amount of time to spend on a task, this can be seen as arranging the layout of the task in the time continuum to facilitate the correct execution of their plan, by allowing more time to cover each step of the plan. This is depicted in Figure 12.6 below. Appendix E Table E.24 reports on 1 interaction strategy/issue related to the distribution of a task plan in the Dialysis activity.

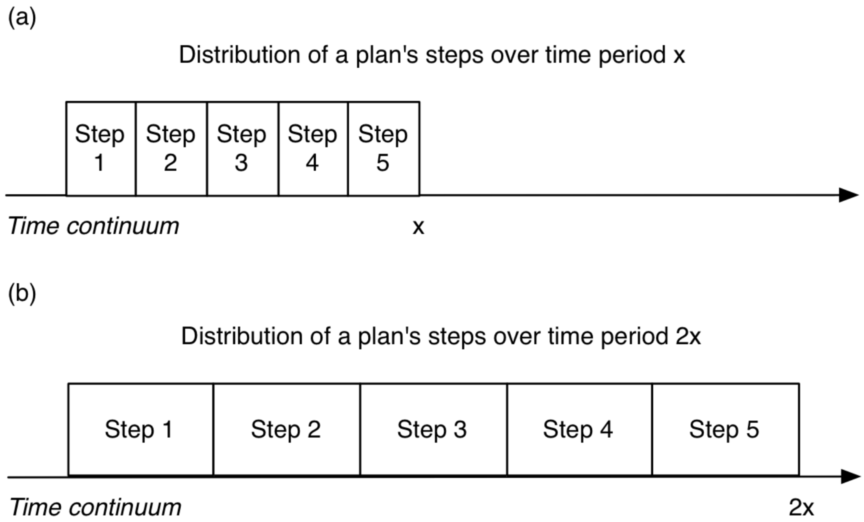


Figure 12.6: Distributing a plan's steps over more time

12.8 Reducing Peak Complexity

In some strategies, participants re-arrange tasks in the time continuum so that there are fewer tasks to do at one point in time, effectively reducing complexity at that point. This is similar to Hutchins's (1995) observation of how precomputations in the context of navigation "redistribute cognitive workload across time"; doing so reduces the amount of work that has to be done in the "high-tempo phases." Many patients like to prepare their dialysis trays well in advance of their next session, such as on the day before the session. The peak complexity of the dialysis treatment is typically just before a particular session. At that point, the patient has to do many tasks before they can start the session.

Out of these tasks, the only two that can possibly be done well in advance of a particular session are the machine disinfection and the preparation of the tray with the items for dialysis. And it was found that many participants indeed do this, particularly with the preparation of the tray. On the day before the next dialysis session, they collect the different items they will need for that session and put these in a tray or box. Figure 12.7 shows two boxes prepared by Alex, the box on the left containing the items required when starting a session (labelled ON) and the box on the right containing the items required when ending a session (labelled OF).

Figure 12.7: Boxes prepared by Alex ahead of next dialysis session.

By gathering the supplies in advance, they will have one less task to deal with before their dialysis session on the next day, effectively reducing peak complexity by shifting that task to an earlier point in the time continuum. This is depicted in Figure 12.8 below. Figure 12.8(a) shows a set of tasks done together, while Figure 12.8(b) shows one task shifted away from the period of peak complexity to an earlier point in the time continuum.

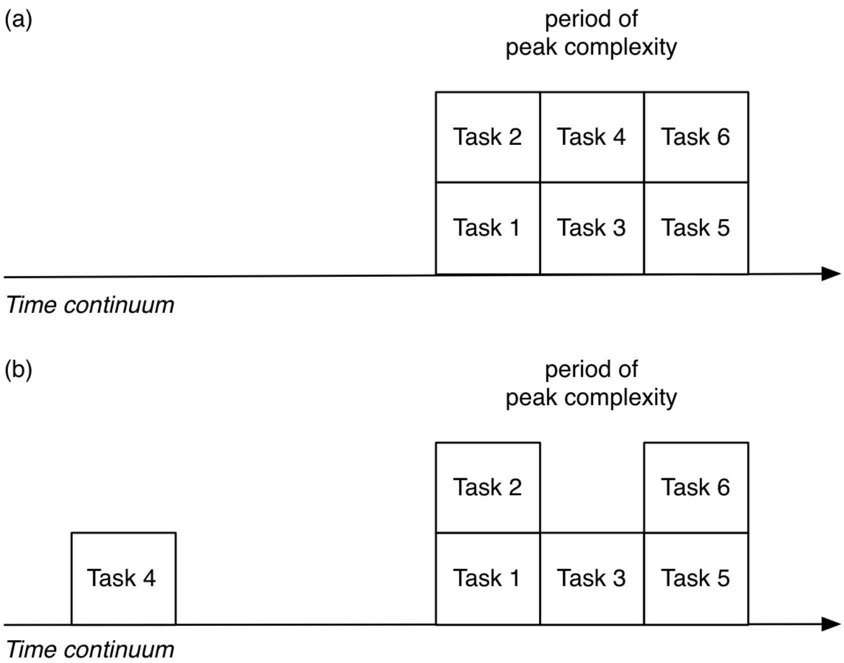


Figure 12.8: Shifting one task away from the period of peak complexity to an earlier point in the time continuum

We can also think of the issue of reducing peak complexity at a point in time in terms of reducing the cognitive load that an actor experiences at that point. In some situations, the physical environment is deliberately arranged such that the number of representations an actor engages at a time is simplified or reduced, as a way of managing cognitive load. Similarly, when an actor re-arranges the temporal layout of a set of tasks and shifts a particular task to another point in the time continuum, this can be seen as reducing the number of task plan representations the actor has to engage with around the time of peak complexity, thus reducing cognitive load.

Bea prepares her tray in advance for another reason also. Once in a while, she needs to go to the hospital to get more bottles of anticoagulant. By preparing her tray one day before dialysis, she gets to check if she is low on anticoagulant and has enough time to get more before her next dialysis session. This is another illustration of the previous principle of performing a certain task early on to help deal with an anticipated problem. Appendix E Table E.25 reports on 3 interaction strategies and issues related to reducing peak complexity in the Dialysis activity. The last four principles presented above show how temporal structures are used to support cognitive processes: actors use the time continuum as representations for task reminders, or arrange the layout of tasks in the time continuum so as to simplify or support their cognitive work.

12.9 Time for Action

Besides being a medium of distributed cognition, and, in a sense, a subject of distributed cognition, as in the above principles, time can also be the object of distributed cognition: actors may distribute cognition through other media to know when it is time to perform an action. Palen and Aaløkke (2006) discuss spatiotemporal relationships in the context of how elderly people manage their medication and describe how some people arrange their medication spatially in a way that represents when the medication should be taken. Similar strategies were found in this study. For example, Fiona keeps two medications that she has to take either in the morning before breakfast or in the evening on top of her dialysis machine, while she keeps the ones she has to take during the day on top of the microwave in the kitchen. In such spatiotemporal distribution of cognition, there is a representation in the physical environment – the spatial position of an object –

and the information the actor encodes for that representation is the time at which a particular task involving that object needs to be done.

Additionally, the representation that indicates when it is time for an action to be performed can also be distributed through technology, which I refer to as technotemporal cueing. Hutchins (1995) observes how, in the context of navigation, the bearing recorder keeps track of a fixed time cycle with the help of either the ship's clock or his own wristwatch. In that scenario, the onus is on the actor to remember to check the time periodically. In contrast, technology can also explicitly prompt the actor at the required time. For example, Alex, who sleeps during dialysis, programs an alarm clock with two alarms: one to wake him up 45 minutes before the end of dialysis, so that he measures and records his blood pressure, and another one to wake him up 30 minutes before the end of dialysis, so that he starts preparing for taking himself off the machine. Figure 12.9 below shows the timer clock on a table next to him, encircled in red.

Figure 12.9: Alex using timer clock, encircled in red, to know when it is time for certain tasks.

Hutchins (1995) adds that some cues help the bearing recorder remember when to monitor the time reference, such as the plotter asking him if it is not time yet. This points to a mix of technotemporal cueing and a kind of socio-temporal cueing. Actors may also rely only on socio-temporal cueing; in the case of some patients, their carer comes to prompt them when it is time to perform an action. Appendix E Table E.26 reports on 4 interaction strategies and issues related to time for action in the Dialysis activity.

12.10 Discussion

12.10.1 A fresh perspective on time as a medium of distributed cognition

This chapter presents a fresh perspective on time in DCog: like the physical environment, technology, and people, time is an external medium which offers possibilities for organizing work to reduce complexity. The examples presented show people's strategies for coping with the following cognitive problems: remembering to perform a task, dealing with anticipated problems, e.g. simplifying choice for the course of action, avoiding errors of omitting steps in the execution of a plan, and reducing peak complexity and cognitive load. In these strategies, people deliberately use temporal structures to support their cognitive work.

For some principles, one may think that all the planning happens in the individual's head, and therefore, time is not involved as an external medium. But there are two things: forming the intention for some actions, and then executing them. These two do not necessarily manifest distinctly, for example, when plans are built on the go, as in the plan-construction interaction strategy discussed by Wright et al. (2000). Still, though the forming of intentions happens internally, the actor must execute his actions through time in the intended fashion. And the time continuum supports flexible execution, just as an actor has to act in some physical environment, and that environment allows the actor to create physical structures to support cognitive work. This time continuum through which the actor executes his plan is external to the actor, just as the physical environment is external to us. Hence, the temporal structures used in the strategies described earlier have both an internal component and an external component, constituting distributed cognition. An actor can change how they lay out their tasks in the time continuum to facilitate their work, just as they can change how they lay out objects in the physical environment to facilitate their work.

12.10.2 Highlighting design problems and opportunities

This perspective on time as a medium of DCog points to a stronger consideration of how time can be used as another medium to support cognitive work. The principles presented in this chapter can help in the evaluation and design of complex socio-technical systems, by helping to understand how actors cope with complexity, when evaluating a system, or by being implemented to reduce complexity, when designing a system. In the context of HH, the consideration of these principles highlighted some design problems and opportunities. As an example of a problem is an issue caused by a particular patient using a temporal routine by association strategy. To remember to take his medication, that patient associated the task of taking his medication with breakfast, a task that has a well-established routine, and this resulted in him taking a blood pressure pill that should be taken after dialysis before dialysis, during breakfast, along with other medications. A possible solution to that problem would be the patient having a new strategy for distinguishing post-dialysis medication from breakfast medication, such as the placement strategy that another patient uses, of locating different medications in different places according to when they need to be taken. As an example of a design opportunity, it was identified that implementing a cue for the end of a session in one particular dialysis machine would help patients. On that machine, patients are advised not to remain connected to the machine for more than a few minutes after their treatment session has ended, to avoid complications related to haemolysis. Preparing for disconnection from the machine can take 10-20 minutes; therefore, patients should ideally start preparing for disconnection well before the end of the session. However, sometimes, some patients fall asleep or get engrossed in other activities and do not realize that it is time to prepare for disconnection; the technology could be designed to prompt patients when it is time to do this.

The existing perspective on time in DCog, that of system evolution, seems to have relevance for socio-technical systems only to the extent of helping to understand how current practice and practitioners have been shaped through time. It has hardly been discussed in studies of socio-technical systems, except by Furniss (2008) and Webb (2008). This new perspective, of temporal structures supporting cognitive work in short-term activity, has direct relevance for the evaluation and design of socio-technical systems.

12.10.3 Applicability of principles in other domains

HH is a domain in which time prominently comes across as a medium that can support distributed cognition perhaps because of the combination of certain attributes of that domain: HH is complex, in terms of the number of actions required to do the treatment, and in terms of the number of related activities that need to be managed; dialysis sessions are frequent and of long duration, such that patients spend a lot of their time on dialysis or related activities; and the home is a setting where people may have few restrictions on how they spend their time, so there are possibilities to configure the use of time to support activity. The result of these attributes is that there is a strong need to reduce complexity in activity, and it is possible to use time to achieve this. Some of these attributes may be applicable to other home self-care therapies or other home activities, and therefore, the principles could be helpful in those contexts. In other domains, considering the temporal distribution of cognition more strongly than just in the sense of system evolution may highlight opportunities for improving socio-technical system design. Hutchins (1995) already illustrates some of these principles in action in the context of ship navigation. As an example of how these principles could be applied, we may deliberately design work such that an actor can flexibly arrange the order, duration, and spacing of tasks such that the complexity in their work is reduced.

12.11 Summary of this chapter

This model focused on understanding the temporal structures involved in the Dialysis activity, helping to understand the temporal context in which patients interact with HHT and their related strategies and issues. It thus contributed to the empirical objective. The analysis also demonstrates that cognition is distributed temporally in immediate activity in the Dialysis activity, contributing to Theoretical Objective 1. The DCog approach allowed a broad range of interaction strategies and issues to be identified, e.g. it highlighted how some patients rely on routines to remember to perform some tasks. To facilitate such analysis, this chapter developed some theoretical principles, fulfilling Theoretical Objective 2.

The work presented in this chapter has been published as:

Rajkomar, A., Blandford, A., & Mayer, A. (2013). Coping with complexity in home hemodialysis: a fresh perspective on time as a medium of Distributed Cognition. *Cognition, Technology & Work*, 1-12.

Chapters 6-12 showed how a broad range of interaction strategies and issues can be identified through a DCog approach, by using the principles associated with the different DiCoT models as lenses. As discussed in Chapter 4, some interaction strategies are complex, in the sense that there are many CFs associated to the strategy, and these factors need to be considered when reflecting on design implications. The next chapter presents an analytical framework of CFs for facilitating the progression from analysis to design implications.

Chapter 13: Contextual Factors Analysis

13.1 Introduction

This chapter presents a new analytical framework of CFs, which helps to progress from the identification of patients' interaction strategies to design implications, by providing an analytical structure for reasoning about the different factors associated with an interaction strategy. Chapters 6-12 presented a range of interaction strategies adopted by patients. There are two main challenges in progressing from the identification of such strategies towards deriving design implications: the complexity of some strategies, in the sense that there are many factors related to them, and the variation in context across patients and in the factors that influence their interaction strategies. The core contribution of this thesis is in understanding the broad range of interaction strategies and issues of patients when interacting with HHT, using DCog as a theoretical framework. The contribution of this chapter is a step further than that; it shows how we can use an analytical structure of CFs to make sense of the complexity of strategies and the variation in strategies across participants, to get general insights for design. Whilst in Chapters 6-12 the design implications of reported interaction strategies and issues were reflected upon at a higher level, without probing deeper for other factors associated with the strategies and issues, this chapter illustrates deeper analyses of strategies. This constitutes the fifth contribution of this thesis. CFA was applied only in the first phase of the main study, as the overall focus of this research was primarily on the DCog analysis.

The objective that this chapter addresses is Methodological Objective 2, of developing an approach for dealing with the complexity of strategies and the variability in strategies across participants, to help progress from analysis to design implications. This objective can be split into 3 parts:

1. To provide an analytical tool for making sense of complex interaction strategies. As described in Chapter 4, DiCoT cannot be readily used to analyse interaction strategies that are related to several CFs in a coherent way. Therefore, the first part of the methodological objective of this chapter is to provide a structure for analysing interaction strategies that are related to several CFs.

2. To provide an analytical tool for facilitating the derivation of design implications from studying the context of use. As discussed in Chapter 4, another limitation of DiCoT is that it does not provide an analytical structure to move from analysis to design implications. Therefore, the second part of the methodological objective of this chapter is to provide an explicit structure for moving from analysis to design implications.
3. To provide an analytical tool for deriving general implications for design while preserving individual participants' contexts of use in the analysis. As discussed in Chapter 4, different patients interact with HHT in different contexts. The DCog analysis was done in a way that avoided an implicit generalisation of the context across participants, by doing an analysis for each principle of each DiCoT model, instead of one overall analysis for each DiCoT model. Similarly, the third part of the methodological objective of this chapter is to derive implications for design at a fairly general level, while preserving the contexts of individual patients in the analysis.

This methodological objective is addressed through a CFA framework that unpacks the CFs related to identified strategies, leading to a rich understanding of the problem and to insights on design implications. The next section describes the CFA framework, expanding on its initial derivation presented in Chapter 4. Section 13.3 then describes how the framework was developed and how it was applied in the first phase of the main study. Then, sections 13.4 and 13.5 present the CFAs of two sets of related strategies. They are followed by a discussion of the interplay among technology design, context of use, and technology use in section 13.6. Finally, section 13.7 discusses how CFA addresses Methodological Objective 2.

13.2 A Contextual Factors Analysis Framework

13.2.1 The 'philosophy' behind CFA

CFA is an approach to studying technology use in context in order to inform interaction design that **explicitly views context as mediating how people interact with technology, through Contextual Factors (CFs)**. A CF can be any aspect of the socio-technical system that influences how people interact with the technology, and is described at the level of a specific actor's context, i.e. it may apply for only one participant of the study or for many. During a CFA, everything, including systems, actors, artefacts, and the technology of interest, is seen as being part of the context. The technology is not viewed as something external to the context; rather, it becomes part of the context, and causes new CFs to exist. This perspective concords with the proposition of moving towards the modelling of context as being relational, dynamic, occasioned, and arising from the activity (Dourish, 2004). I argue that to understand how well a technology fits in a 'context', we need an analytical perspective in which the technology is part of the context (part of the whole) – then we can see what kind of behaviour (interaction strategy) emerges, and the role that technology design and/or other aspects of the context play in that strategy. Thus, when understanding why an actor has a particular strategy, an aspect of technology design may become a CF for that interaction strategy.

The main aim of the CFA approach is to provide a structure for analysing the different parts of a complex interaction strategy together, effectively preserving the richness of the context in which that strategy happens. A consequence of explicitly considering CFs in this manner is that a rich picture of how the context influences interaction strategies is painted, including the trade-offs and decisions that people make. This effectively facilitates a natural progression from studying the context to deriving implications for design, deployment and training. Though the end-goal of a CFA is to derive implications for design at a general level, the specificity of each participant's context is acknowledged during the analysis.

13.2.2 The methodology of CFA

As illustrated in Chapter 4, when patients interact with HHT, they employ certain interaction strategies, which can be *optimising strategies,* e.g. doing the interaction faster to save time, or *coping strategies,* e.g. to deal with a difficulty they face during the interaction. After identifying these interaction strategies and related incidents and issues, we can unpack the *contextual factors* that are related to them. A CF has a *relation* to the interaction strategy:

- it can be the *motivation* for employing the strategy;
- it can describe the *background* of the strategy;
- it can be the *result* of the strategy being employed (which may include viewing the strategy itself as a CF, especially since a particular strategy can be a CF for another strategy);

- it can *enable* the strategy, similar to how an "enabler" factor (Sharples et al., 2012) makes it possible for a user to use a medical device at all;
- it can *constrain* the strategy, limiting its effectiveness;
- or it can be *deprecated* by the strategy (e.g. traded-off to prioritise another CF).

Note that not all of these types of CFs will necessarily be relevant in the analysis of a particular strategy; the types that are relevant will depend on the nature of the strategy and on the research question. Also, one may identify other types of CFs that are relevant for their research question. Based on insights from the CFs, we can derive *design implications* that, if implemented, could improve people's experiences of using the technology of interest. Design implications may pertain to the design of the socio-technical system, and not necessarily just the technology, and therefore may include implications for training or for the deployment of the technology.

The process of a CFA, as shown in Figure 13.1, is: 1) identify interaction strategies and related issues and incidents; 2) analyse CFs related to these strategies; and 3) reflect on design implications. In the first step, a set of related strategies from several participants can be considered together, and then in the second step the CFs of each strategy can be unpacked. Then, in the third step, reflections on design implications can be made across these strategies, effectively leading to general insights for design by identifying common patterns across participants, while preserving individual participants' contexts during the analysis.

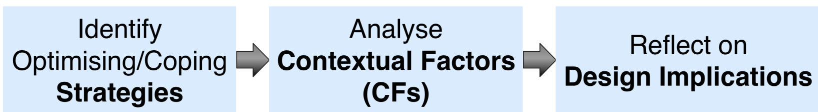


Figure 13.1: Process of CFA

The baseline perspective when doing a CFA in this study is a patient interacting with HHT in the Dialysis activity, and the analysis aims to understand the CFs that motivate, result from, enable or constrain a certain interaction strategy, or that provide background information for it. These CFs can belong to the HHS or to another system. From this baseline perspective, an *optimising* strategy is one in which the patient is already able to achieve the intended outcome of interacting with the technology, but tries to optimize the interaction, e.g. to save time or increase other benefits such as comfort. The patient may take advantage of some aspect of the TS or of the broader system to achieve this. An optimizing strategy can also be adopted to allow the patient or carer to undertake other activities on top of the Dialysis activity, e.g. installing an intercom system between the dialysis site and the kitchen, so that the carer can do things in the kitchen during dialysis. A *coping* strategy is one in which the patient faces some difficulty in achieving the intended outcome of interacting with the technology, and adopts that strategy to cope with the difficulty, e.g. not being able to prime the line the normal way, and therefore using a syringe. The difficulty can be due to limitations of the user, the TS, or the broader systems. A coping strategy can also be adopted to mitigate negative effects that interacting with the technology has on the broader systems. The next section describes how CFA was developed and how it was applied in the first phase of the main study.

13.3 Methods

The first part of this section describes how CFA was developed, and the second part describes how it was applied in the first phase of the main study.

13.3.1 Development of the CFA framework

CFA was developed during the preliminary study and the first phase of the main study. As discussed in Chapter 4, in the preliminary study, complex interaction strategies were identified, which involved several CFs. As no existing analytical tool supporting reasoning about such strategies and their associated factors was found in the literature, and as the explicit consideration of the CFs related to the strategies seemed to provide a way forward for making sense of the strategies, CFA was developed. An open qualitative analysis of some strategies identified in the preliminary study was conducted, and different types of CFs were identified. Two types of strategies were identified: coping strategies, as discussed in the existing literature, but also optimizing strategies. The framework was then applied and refined during the first phase of the main study. It may be possible to identify more types of CFs. The types presented in this chapter were found to be sufficient for the purpose of this thesis, which is to understand interaction strategies and issues to inform design, including understanding the motivations for strategies, the factors that enable strategies or constrain their effectiveness, and the trade-offs being made in strategies. The next section describes how CFA was applied in the first phase of the main study.

13.3.2 Application of CFA in the first phase of the main study

CFA was applied on the same data set as that of the DCog analysis for the first phase of the main study, i.e. data gathered during the preliminary study and during the first phase of the main study, from 8 patients, 1 home nurse, 1 technician, through short observations, still pictures, and audio-recorded semi-structured interviews. During interviews with patients, they were asked for more detail on their motivations for doing things in certain ways, so that data on the CFs related to their interaction strategies could be elicited.

Data analysis was conducted in the following steps:

1. The data from the first visit to the participant was coded in ATLAS.ti for Optimising Strategies, Coping Strategies and Contextual Factors. The data had already been coded for Incidents and Issues during the DCog analysis. Eleven codes were used in ATLAS.ti, and these codes and an example of a coded interview transcript (for Gina) are in Appendix F section F.1 (note that in the screenshot in the appendix, the codes Practices_Coping and Practices_Optimising refer to Coping Strategies and Optimising Strategies respectively).
2. At the end of the coding process, a document containing all the quotations (coded sections of a document) for that participant was generated. An example of this document (for Jill) is in Appendix F section F.2.
3. Then, the quotations in that document were analysed and highlighted with a colour to indicate whether they pertained to the same interaction strategy or a different one. Then all quotations with the same colour-code were grouped together, and these formed a set of phenomena (strategies, issues and incidents) for a particular interaction strategy. An example of a colour-coded and structured quotations document (for Jill) is in Appendix F section F.3.
4. An entry was made in a spreadsheet for each interaction strategy identified for the participant, with an indication of the number of quotations of strategies, issues and incidents for that particular interaction strategy. Appendix F section F.4 shows a sample of this spreadsheet.

5. Then, any still pictures and sketches of the physical layout and of artefacts that were taken for this participant were analysed, and if these informed any of the identified interaction strategies for that participant, a note was made in the record for that interaction strategy. An example of such a note is in Appendix F section F.5.
6. If there was an open point about a quotation or a picture, i.e. clarification from the participant was required, a note was made in the home visit guide for the second visit for that particular participant. Examples of points for clarification during the second visit (for Gina) are in Appendix F section F.6.
7. Steps 1 to 6 were repeated with the data gathered during the second visit to the participant, and any obtained clarifications about open points were noted in the spreadsheet. An example of an entry of a clarification in the spreadsheet (for Gina) is in Appendix F section F.6. Also, during the second visit, key incidents that had been identified in the data from the first visit were explored in greater depth with the participant, both to get a richer understanding of the incident and to validate my understanding of that incident.

In all, 309 quotations were analysed, out of which 151 were new ones created during the CFA and 158 were a subset of the existing ones created during the DCog analysis. 110 strategies, each consisting of several related quotations, were identified across the 8 participants. These strategies were grouped into 13 groups. The strategies in a particular group were similar in terms of the type of problem they pointed to, at a high level of abstraction. Appendix F section F.7 shows these 110 strategies, and Appendix F section F.8 shows the grouping of strategies for the first two groups. The 13 groups are presented in Table 13.1 below. Two sets of strategies, each from a group, were selected for further analysis. The distinction between a group of strategies and a set of strategies here is that the strategies in a set are more closely related, at a lower level of abstraction. These two sets, italicized in Table 13.1, are: optimising on time spent with dialysis, and remembering to perform certain steps. Note that there are other strategies in the groups to which these two sets belong; I focus on these two sets as they involve closely related strategies. The quotations for these strategies were further analysed to unpack the CFs related to them. Then, for each set, reflections on design implications were made across the strategies of that set.

Table 13.1: Groups of optimizing and coping strategies

Home adapting to dialysis constraints and vice-versa
Planning dialysis to accommodate home activities
Optimising on time spent with dialysis
Optimising on comfort and peacefulness
Doing entertainment activities while on dialysis
Optimising space use
Positioning of patient, machine and other artefacts
Other people intervening in emergency or helping out
New alarms at home, and dealing with difficulties
Remembering to perform certain steps
Troubleshooting strategies
Fixing things to save time and keep dialysis going
Different practitioners having different approaches, and patients consulting other patients

In the next two sections, the CFAs of these two sets of strategies are presented. These two particular sets of strategies were chosen because they involve related strategies from several participants. Depending on the research question, future work could, for example, focus on a specific aspect of the design of HHT, and perform CFAs with the relevant strategies. Also, note that for several strategies discussed in Chapters 6-12, CFAs would need to be performed on them to reach design recommendations that better account for the complex reality of the context, which often involves trade-offs among different factors. While discussing these strategies in those chapters, I reflected on their implications at a high level, without probing into other factors. The next two sections illustrate deeper analyses of strategies through CFA.

13.4 Optimising on time spent on the Dialysis activity

Some participants adopt optimizing strategies to minimize the time they spend on the Dialysis activity, either to have more free time or to minimize the duration of a stressful and tiring experience. Three strategies are considered in this section: Adam doing the lining of the circuit during the disinfection phase; Jim doing the lining of the circuit while the machine is self-testing; and Carl increasing the blood pump speed during connection.

Adam was expecting that with the machine at home, he would have more free time. However, he feels that now he has less free time, as he dialyzes on more days, since that is better for his health, and he has to do the disinfection of the machine himself (whereas in the unit he would only dialyze on three days, and the nurses would already have done the disinfection of the machine). Consequently, to save time spent with his treatment, he tries to ensure that the time between the start of the disinfection and the finishing of treatment is "as squeezed as possible", and he tries "not to lose any minute." Therefore, he adopts a strategy of lining the machine and priming the line while the machine is disinfecting. Normally, patients are taught to do the lining and priming after the disinfection. According to the technicians, this is not the way the technology was meant to be used, but with M1 specifically there is no safety risk. Table 13.2 below summarizes the CFs for this interaction strategy. The table acts as a representation that captures the different contextual factors associated with a strategy together. Note that, depending on the purpose of the analysis, it may be possible to probe deeper into an interaction strategy for more CFs.

Table 13.2: Adam lining machine during disinfection on M1

Relation to Strategy	Description of Contextual Factor
Motivation	Adam wants to minimise the time he spends on the Dialysis activity, to have more free time
Enabling	Lining and priming can be done during disinfection, though this is not the taught way of using the technology
Result	Adam does the lining of the machine and primes the line while the machine is disinfecting

To minimize time spent on the Dialysis activity, Jim sometimes does the lining of the circuit during the 'T1 test' (the machine's self-testing phase), instead of after it, as taught by Nelly. Nelly teaches patients of H3 who use M5 to do the disinfection, then the T1 test, and then the lining. This is because, if the lining is done in parallel with the T1 test, and the test fails, the line set and the dialyser would need to be scrapped and would thus be wasted. This is summarized in Table 13.3 below.

Table 13.3: Jim lining during T1 test on M5

Relation to Strategy	Description of Contextual Factor
Motivation	Jim likes to minimise time spent on the Dialysis activity
Result	Jim sometimes does the lining during the T1 test, instead of after it
Deprecated	To avoid wasting a line set and a dialyser in case the T1 test fails, Nelly teaches patients of H3 who use M5 to do the disinfection, then the T1 test, and then the lining.

According to Carl, Bob's son and carer, Bob gets very stressed and tired with his treatment, and likes to "get it over and done with as soon as possible". Therefore, Carl tries to get Bob's treatment done in as little time as possible. When connecting or disconnecting Bob from the machine, Carl has to wait for the blood to go through the dialyser. Since this takes a few minutes, Carl increases the blood pump speed from 150 ml/s to 200 ml/s, so that Bob's blood moves faster within the extracorporeal circuit, and dialysis can be started sooner. Note that during dialysis, Carl has to set the blood pump speed to what the consultant prescribed for Bob, to maintain Bob's cardiovascular stability. This is summarized in Table 13.4 below.

Table 13.4: Carl increasing blood pump speed during connection

Relation to Strategy	Description of Contextual Factor
Motivation	Dialysis is very stressful and tiring for Bob, who likes to get it done as quickly as possible
Enabling	The technology allows the blood pump speed to be changed at any point in the treatment
Result	Carl increases the blood pump speed during connection and disconnection, to speed up the flow of the blood in the circuit

Implications of strategies for optimizing on time

From the three optimizing strategies described above, we see how a patient/carer may plan the tasks involved in the Dialysis activity so that the dialysis treatment can be started and ended as soon as possible, in some cases with a sort of 'getting it out of the way' attitude. To achieve this, a patient/carer may take advantage of aspects of HHT design to save time, in ways not necessarily intended by designers. Recognizing patients' desire to complete dialysis as quickly as possible, designers and trainers should consider which such strategies can safely be built into the design or use of HHT.

13.5 Remembering to perform certain steps

Some participants adopt coping strategies so that they remember to perform certain steps. Three strategies are considered in this section: Gina referring to a note to remember to change the sodium setting; Carl relying on a visual grouping to remember to change the sodium setting; and Adam laying out all dialysis items on a table to remember to inject the anticoagulant.

Initially, when the technician set defaults for treatment parameters on Gina's machine, he set the default setting for the sodium to 136, to match her dialysis prescription. However, later on, since she started having low blood pressure post-dialysis, the consultant asked her to increase the sodium setting to 138. Gina forgot to change the sodium setting on some occasions, and therefore she put a note on the machine's interface to remind her to change the sodium setting every time she is programming a treatment session. It would be possible for the technician to visit her again and change the default setting on the machine to 138. However, the sodium setting that Gina needs is likely to fluctuate again, and therefore this is judged as not being worth the effort. The need for the patient to be able to adjust the sodium setting applies only to patients of H1. H3 and H4 regard sodium profiling as a bad practice. Their patients are not asked to change the sodium setting, and the setting is blocked on patients' machines. This is summarized in Table 13.5 below.

Table 13.5: Gina referring to note to remember to change sodium setting on M2

Relation to Strategy	Description of Contextual Factor
Motivation	Gina needs to change the sodium setting on her machine from 136 to 138 for every session. On some occasions, she forgot to change the sodium setting.
Background	H1 does sodium profiling, and therefore the nephrologist may request a patient to change their sodium setting. This is not the case with H3 and H4, as they regard sodium profiling as a bad practice, and the sodium setting is blocked on patients' machines.
Background	Only the technician can change default settings on the machine. The patient is not allowed to, as a safety precaution.
Background	Getting the technician to change the default sodium setting is deemed not worth the effort by Gina, the nurse and the technician, as the sodium setting that Gina needs is likely to fluctuate again
Result	Gina put a note on the machine's interface to remind her to change the sodium setting every time

Carl also needs to change the sodium setting every time he programs a session for Bob. On M1, which Carl uses, the sodium setting is displayed on the same screen as the main parameters that need to be programmed, e.g. volume of fluid to be removed. Carl reports that this helps him to remember to change the sodium setting every time. This is summarized in Table 13.6 below.

Table 13.6: Carl relying on visual grouping to remember to change sodium setting on M1

Relation to Strategy	Description of Contextual Factor
Motivation	Carl needs to change the sodium setting on Bob's machine from 13.9 to 13.8 for every session
Enabling	On M1, the sodium setting is displayed on the same screen as the main parameters that need to be programmed, e.g. volume of fluid to be removed
Result	Carl remembers to change the sodium setting by seeing it next to the main treatment parameters

Referring back to Gina's strategy discussed above, on M2, which she uses, the interface consists of many small displays and buttons, and therefore the sodium setting is not next to the other parameters; whereas on M1 everything is integrated on a touchscreen. This illustrates how CFs for similar strategies can vary across patients, in this case because of differing technologies.

Adam used to forget to inject the anticoagulant into the circuit before starting dialysis. To cope with this, he lays out all items on a table at the beginning of his preparation for dialysis so that, seeing the anticoagulant on the table, he will remember to inject it before starting dialysis. On one occasion, a random object that was on the table occluded the anticoagulant, and he forgot to inject it. This resulted in blood clotting in the circuit, and he had to scrap it and start all over again. Adam also reported that, in his rush to prepare for dialysis and get the treatment done as quickly as possible, he sometimes forgets to even place the anticoagulant on the table in the beginning. M1, which he uses, does have a heparin (an anticoagulant) pump integrated into it, and it can prompt the patient to inject the anticoagulant. However, H1 prefers to use another anticoagulant, tinzaparin, which is simpler to use, but then the integrated pump is bypassed. This is summarized in Table 13.7 below.

Table 13.7: Adam laying out items to remember to inject anticoagulant

Relation to Strategy	Description of Contextual Factor
Motivation	On some occasions Adam forgot to inject the anticoagulant into the circuit
Background	M1 does have a heparin (an anticoagulant) pump integrated into it, which could potentially help Adam in dealing with the step of injecting the anticoagulant.
Background	However, H1 prefers to use another anticoagulant, tinzaparin, and therefore this integrated pump is not used.
Result	Adam lays out all items on a table at the beginning of his preparation for dialysis to remember to inject the anticoagulant
Constraining	Once, another random object on the table occluded the anticoagulant, and Adam forgot to inject it
Constraining	Once, Adam forgot to even place the anticoagulant onto the table in the beginning, and consequently forgot to inject it

Implications of strategies for remembering steps

The three coping strategies discussed above illustrate how, in some situations, even though the technology has been designed to provide assistance to the patient, e.g. by allowing the sodium setting to be pre-set to a certain value, or by having an integrated anticoagulant pump, the complexity of the system in which the technology is used can limit this assistance. For example, the sodium setting that the patient requires can fluctuate, or the hospital may prefer the use of a different anticoagulant than that supported by the technology. Still, the design of the technology may help a patient in dealing with this complexity to some extent, e.g. on M1 having the sodium setting on the same display as the other treatment parameters helps Carl to remember to change the sodium setting. The next section discusses the interplay among technology design, context of use, and technology use.

13.6 Interplay among technology design, context of use, and technology use

During a CFA, technology design and technology use are viewed as part of the context, i.e. as CFs. In this section I consider them separately, as Technology Design, Context of Use, and Technology Use, to illustrate the triangular interplay among them. We revisit the example of Carl getting Heidi to start the disinfection of the machine while he is on his way to his parents' home. This example, in itself, shows three types of interplay. Firstly, the way an actor interacts with technology may depend on both the design of the technology and the context of use, as shown in Figure 13.2 below. Carl gets Heidi to do the disinfection (an optimizing interaction strategy, which maps to Technology Use) to save him time because the disinfection process takes 50 minutes (which maps to Technology Design). It is possible for him to adopt this strategy because Heidi is available as an actor in the system (an enabling CF, which maps to Context of Use).

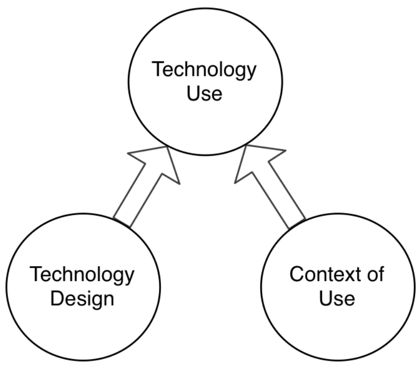


Figure 13.2: Technology Use being shaped by Technology Design and Context of Use

Secondly, to accommodate certain ways of interacting with the technology, based on the context of use, an actor may augment the TS (changing the design), as shown in Figure 13.3. To allow Heidi to do the disinfection (i.e. to accommodate this interaction strategy), Carl put stickers on the machine's interface to indicate which buttons she needs to press (i.e. augmenting the design), because Heidi is illiterate and has not been trained on using the machine (the CF which makes the design augmentation necessary).

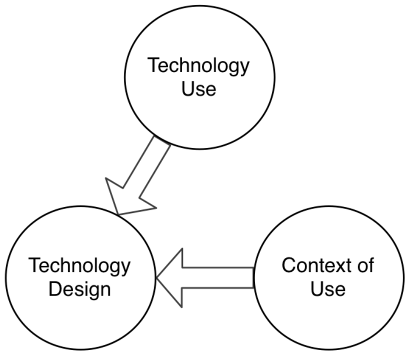


Figure 13.3: Technology Design being shaped by Technology Use and Context of Use

Thirdly, the way a technology is used, in combination with the design of the technology, may have effects on the context, as shown in Figure 13.4. For example, every Tuesday, Carl needs to do a special disinfection programme, by changing the disinfection mode of the machine. However, after the disinfection is done, the machine stays in that special mode and does not revert to the normal mode (a design aspect of the technology, arguably a limitation). Since it is too complicated for Heidi to change the disinfection mode, Carl visits his parents again on Tuesday evening (the effect on the context) to set the machine back to the normal disinfection mode, so that on the next day Heidi can start the disinfection (the interaction strategy or technology use to be accommodated).

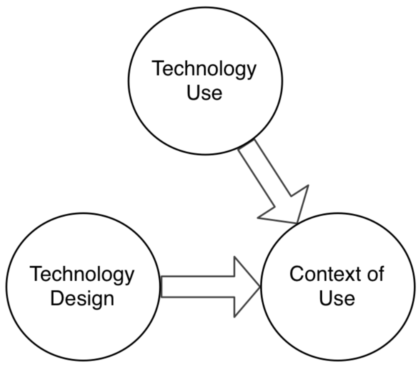


Figure 13.4: Technology Use and Technology Design affecting the Context of Use

The set of strategies presented on optimising on time spent on the Dialysis activity shows how some patients use the technology in unforeseen ways, by leveraging aspects of the Technology Design, due to the Context of Use. The set of strategies presented on measures to remember to perform certain steps, shows how (the complexity of) the Context of Use limits the extent to which Technology Design can assist a patient, leading the patient to adopt certain coping strategies (Technology Use). Knowing that there are these types of interplay can help to structure data gathering and analysis, and help to understand how different CFs are related to a particular strategy when doing a CFA. The next section reviews how CFA addresses Methodological Objective 2, and how it is different from existing approaches to studying context.

13.7 Discussion

13.7.1 Analysing complex interaction strategies

CFA helps address the three parts of Methodological Objective 2. Firstly, as shown in the examples of strategies presented above, the explicit consideration of the CFs related to a particular interaction strategy provides a structure for analysing complex interaction strategies. The CFs chain together the different aspects of the strategy, allowing it to be analysed coherently. Secondly, as demonstrated through the examples presented, exposing the CFs related to a particular interaction strategy gives a rich understanding of that strategy and of potential design issues related to it, helping to provide traction to move from analysis to design. Thirdly, by considering a set of related interaction strategies from several participants, analysing the CFs for each strategy, and then reflecting on design implications across the set of strategies, we can derive design implications across participants while preserving the specificity of each participant's context during the analysis.

13.7.2 Difference from existing approaches to studying context

The key feature that distinguishes CFA from other approaches to studying context is the attempt to provide *a structure for analysing a complex interaction strategy coherently,* to derive design implications while preserving the richness of specific participants' contexts. To achieve this, it puts context centre stage in the analysis, through CFs. While the CFA approach shares some basic assumptions with Activity Theory (AT) (Kaptelinin & Nardi, 2006), e.g. that an actor engages in purposeful activity and that interactions happen in a broader context, AT is more of a 'theory of everything', whereas CFA is a lightweight tool that specifically aims to help make sense of complex interaction strategies to inform interaction design. In a sense, a CFA is a root-cause analysis of interaction strategies to inform design.

13.8 Summary of this chapter

This chapter presented a CFA framework that addresses two challenges of studying patients' interaction strategies and issues to inform technology design. Firstly, some strategies are complex in the sense that there are several factors related to them, and these need to be considered when reflecting on design implications. Secondly, the factors involved in a strategy may differ across patients, as there is significant variation in the context in which patients use HHT. CFA addresses the first challenge by unpacking the CFs related to a complex strategy, to give a rich understanding of that strategy. It addresses the second challenge by considering a set of related strategies from several participants, unpacking the CFs related to the strategies, and then reflecting on design implications across the set of strategies.

Chapter 14: The Patient Experience of Interacting with HHT

14.1 Introduction

This chapter reflects on the patient experience of interacting with HHT, based on the strategies and issues identified in this research. It presents an account of the patient experience in terms of four inter-related aspects of interacting with HHT: learning to use HHT; safety during dialysis; usability of HHT; and coping with the complexity of HH. In chapters 6-12, I prioritized the reporting of strategies and issues that had potential safety implications, as these are of key interest for this research. In this chapter, I also consider three other aspects of the patient experience. For each aspect, I discuss elements of HHT design that currently contribute to a positive patient experience, and make recommendations that could potentially improve the patient experience. Together with the analyses presented in chapters 6-12, this chapter fulfils the second contribution of this thesis, of understanding the patient experience of interacting with HHT in terms of the contexts of interactions and patients' interaction strategies and issues.

14.2 Learning to use HHT

HH is probably at an extreme of complexity for a home self-care therapy. A patient is trained intensively on doing their treatment at the dialysis unit for several weeks or months, and the training does not cover everything in detail. When a patient first starts using their machine at home, they typically face teething issues and make mistakes. They continue learning at home, from their own experiences, e.g. when they encounter new situations they did not go through in the training or when they learn by trial and error, and from the nurse and the technician. Things gradually make more sense, and eventually, the patient becomes an expert in using HHT to perform their treatment.

Wong et al. (2009) portray the experience of a patient learning to use dialysis equipment as a psychosocial phenomenon. Whilst the patient experience can be improved by clinician educators being more attentive to self-treatment as a socially situated activity, as suggested by Wong et al. (2009), the interface design of HHT can also contribute to a smooth learning experience for the patient. For example, since M5 provides contextual information to the patient and walks the patient through step by step for many tasks, there is no need to overload the patient with information during the training; they can continue learning at home through the technology. This also helps them to deal with situations for which they learnt the procedures during the training, but forgot the procedures since those situations happen very rarely.

One major improvement that could help patients in the learning process would be the use of telemonitoring, at least in the early stages of their treatment at home, to provide a direct channel between the patient's machine and clinicians and technicians. Cafazzo (2010), in the context of patients transitioning to nocturnal HH, suggests that telemonitoring would help patients cope with teething issues. This would also be applicable in the context of patients transitioning from satellite unit haemodialysis to HH. According to Nancy, a home nurse, she gets to know of more issues that patients are facing when she visits them at home, as they tend not to phone her as they don't want to bother her. With telemonitoring, it might be that patients would feel more encouraged to seek help from the nurse, as the connection to the nurse is, in a sense, 'already there'. It could be combined with features such as video chat to mimic the face-to-face communication that happens when the nurse visits the patient as closely as possible. According to the technicians who participated in the studies, some of the main issues that make troubleshooting machine alarms over the phone hard are, firstly, patients having different terminologies for machine parts and, secondly, technicians having to rely on their mental visualization of what is happening. In some cases where the technician cannot ascertain the problem from the phone conversation, the technician has no choice but to ask the patient to come off the machine and lose the blood that is currently in the circuit. With telemonitoring, the technician could see exactly what the problem is on the machine, and hence provide optimal support to the patient. As some patients seem to prefer to consult other patients instead of clinicians, another potential improvement would be for HHT to support patient-patient networking, allowing patients to share experiences and benefit from the knowledge of expert patients.

One finding of this study with broader implications is that the variations in practices across nurses and hospitals can influence the interactions of patients with HHT. While some patients strictly stick to the specific steps they learnt during their training, others are influenced by other practices they observe. For example, they get confused on what they should be doing, or they incorporate some aspects of those practices into their interactions with HHT. Sometimes, other actors from the SS can have perspectives on how to do a patient's dialysis treatment that are different to those of actors of the HHS, or even conflicting ones. This stresses the importance of supporting patients in building knowledge and facilitating their access to information on HH, so that they can make their own informed decisions on how to use HHT. Godbold (2013) similarly recommends that renal patients be supported in developing "their own authority."

14.3 Safety during dialysis

HH is an invasive, safety-critical treatment. There are inherent risks of patient harm during dialysis treatment that need to be mitigated, e.g. hypotension followed by exsanguination; blood leak; air embolism; and blood clotting followed by haemolysis. These are explained in Appendix A section A.2. Moreover, dialysis treatment is complex, requiring many steps to be performed correctly and in the right order for treatment to be safe. Doing a step incorrectly could lead to patient harm.

Fortunately, current HHT seems to be very safe and the design is foolproof in mitigating safety risks, when used as designed, and for things that are within the scope of what the technology can detect. Incidents in which patients are harmed are extremely rare. The design is effective in ensuring that all required steps are performed before letting the patient proceed to treatment. This gives patients confidence in doing their treatment independently. In fact, some patients rely on the safety-consciousness of the machine during interactions in the early stages of learning; they make mistakes, and learn through these, knowing that the machine would not let them proceed to treatment if they missed a step. This allows them to gradually learn how to perform a complex treatment. Another positive aspect of the design of M5 in particular that contributes to safety is that it allows a helper with little or no training to intervene in a hypotensive episode: a single button press is required, which both dispenses fluid to the patient and suspends fluid removal. To ensure their safety, many patients adopt strategies that involve other people, therefore the design of HHT should allow lay people to intervene in case of emergency.

Some steps in a dialysis session are outside the scope of what current HHT can detect, and therefore the technology cannot ensure that the patient does them correctly. For example, when re-lining the circuit during the washback phase, the machine cannot tell whether the patient wrongly connected the ends. In the fatal incident discussed by Allcock et al. (2012), the patient connected the arterial end of the circuit instead of the venous end to the saline bag, resulting in exsanguination. Since current HHT cannot detect this, it is important to use other methods to mitigate this risk, e.g. making the colour-coding clearer so the patient can easily distinguish between the two ends, as recommended by Allcock et al. (2012).

Doing dialysis at home allows a carer to engage in other activities during dialysis, and it is therefore likely that a carer will be away from the dialysis site during dialysis. Hence, one improvement to the patient experience in terms of safety would be the provision of a communication channel between the patient and carer, so the patient does not have to rely on calling out loud for the carer in case of emergency, as is the case for some participants of this study. For some patients, this problem is compounded by the fact that they cannot reach the machine themselves to start the emergency procedure. One way to deal with this, as done by Beth, is to have an extension of the emergency button positioned right next to the patient, on their chair. Also, some patients dialyse when they are completely alone at home, even though this is strictly against the policy of their hospital. Extra support could be provided to such patients through telemonitoring. For example, the measures for dealing with hypotension could be triggered remotely and support staff could call for an ambulance if needed. One key piece of information that helps a carer ascertain whether the patient is well during dialysis is their blood pressure. In some cases it can be hard for the carer to check the blood pressure of the patient, if e.g. they are asleep. One improvement to the patient experience would be the display of the patient's blood pressure on the interface of HHT. This would help patients and carers in anticipating hypotensive episodes, so they can take measures accordingly.

Some strategies identified in this study involve patients/carers deliberately taking safety risks and attempting to fix a problem with their machine themselves, under the pressure of the patient needing to dialyse soon to feel better. For example, once Carl fixed a water leak behind the machine with some tape and proceeded to dialyse his dad, even though the technician told him not to use the machine until he came to fix the leak. Another example is that once Garry used a hair dryer to dry some water inside his machine that was preventing the machine from proceeding to preparing the dialysate batch. A crucial factor in these strategies is the desire of the patient to dialyse as soon as possible, so they can get rid of toxins from their body and feel better. Another factor is that, when a home patient's machine has broken down, it can be problematic for them to arrange to dialyse in the dialysis unit. These factors may lead them to adopt potentially unsafe strategies, as in the examples. This shows how the setup of the broader system of care influences the safety of patients' interactions with HHT.

14.4 Usability of HHT

The usability of HHT can be viewed as being linked to the patient experience in terms of: the ease of using it, how well it supports the patient in their treatment during the Dialysis activity, and how well it fits in patients' other activities.

Many strategies and issues identified in this study that are relevant for usability are related to the troubleshooting of problems during the Dialysis activity. While some representations of information on HHT's interface are very useful for patients and help them deal with problems, such as the real-time representations of pressures inside the dialysis lines that help patients deal with arterial/venous pressure alarms, some representations are not meaningful to patients. For example, in some cases though the machine alarms and attempts to tell the patient what the problem is, the machine's message is not really understandable by the patient. The design is good from a safety perspective, as it does not allow the patient to proceed with treatment if there is a problem, but the design is not effective in supporting the patient in solving the problem. The patient experience could be improved by having messages that do not contain technical terms and are simpler to understand. Where possible, the technology should also mention possible causes of or even solutions for the problem, instead of simply stating that there is a problem, and additionally attempt to narrow down the source of the problem as much as possible. The design of M5 makes improvements in this direction, and patients benefit from it. Besides helping the patient to deal with the problem themselves, making them feel more independent in their treatment, having meaningful messages has other benefits. Firstly, it may alleviate the need for the patient to consult the manual. It was found that, while some patients find using a manual helpful, others do not, or consulting the manual is not a practically viable option for them, as e.g. they are on their own and it is not easy to manipulate a big manual with one hand. Secondly, it helps the patient decide whether a nurse or technician should be contacted if they need assistance. Thirdly, in the absence of telemonitoring, it then allows the nurse/technician to get a better understanding of what the problem is as the patients reads the message to them. Also, ideally, coordination of problems with the other components of the TS should be integrated into next-generation HHT, to minimise the detective work that patients have to do when troubleshooting. This echoes the recommendation of Kenley (1996) that the highest value renal therapy can be achieved through holistic product design, through design features such as automated system disinfection and integrated water purification.

Another improvement that would make HHT easier to use would be to reflect that a patient’s treatment plan can vary. A patient may have different possible plans for their treatment, e.g. Adam sometimes needs to use a different acid concentrate. When he uses the one that is not programmed for him in the machine, the machine alarms. He has to reset the alarm a couple of times and then he can proceed. The technology could accommodate different treatment plans, and coordinate the patient’s treatment accordingly.

For several patients and carers, the trickiest part of the treatment is doing the needling. For patients, the main challenge is the affective issue of having to insert needles into their arm. For carers, besides the affective issue of having to puncture their dear one’s skin, there is also the practical issue of finding the right channel and angle for inserting the needles. Unlike a patient who is self-needling, a carer cannot ‘feel’ for the right channel and angle, and they rely on feedback from the patient. Ideally, next-generation HHT should assist patients and carers in doing the needling, e.g. using affective technology to help patients cope with the pain of needling and using sensor technology to guide carers with the needling.

At a higher level, to better fit in the home environment, HHT should ideally be designed in consideration of the requirements of other activities that happen in the home. For example, HHT noise levels should be minimized as far as possible to not disrupt the sleep of family members or neighbours, and HHT aesthetics should fit in the home so that patients do not have an additional problem of how to conceal the machine. Dialysis consumes a lot of the time of patients and carers, and they typically try to find ways to optimise the time they spend on the Dialysis activity. HHT should support patients in this where possible, e.g. by designing the interface such that a helper with little or no training can start the disinfection process on the machine while the patient or carer is on their way back home, or such that the disinfection process can be started remotely.

Some aspects of the design, deployment or use of HHT involve trade-offs between different features of usability or between safety and usability. For example, while M3 is portable and the patient can travel with it, thus increasing its usability in a certain sense, the fact that it is smaller means it does not have an air bubble trap, which automatically gets rid of air bubbles in the circuit, and consequently the patient has to manually remove air bubbles with a syringe. This decreases its usability in another sense. As an example of a trade-off between safety and usability, there are some parameters that the technician presets on the patient's machine and the patient is not given rights to modify these preset values, as a safety precaution. However, this means that during a phase when the patient has to use a different value than that preset, e.g. a different sodium setting, they need to remember to change that parameter value before every session, defeating the purpose of having a preset. Also, it is arguable whether HHT should always strictly enforce that the patient fulfils all expected steps. In some situations, having an 'override mode' in which the machine grants the user leeway could be beneficial. For example, once when Eva was not well, her son panicked and wanted to quickly administer a bolus of saline to her. Since he was in a rush, he administered the saline without performing all expected steps, and the machine kept popping up a message alerting him to the steps he did not perform. This stopped the dialysis, and eventually he had no choice but to take Eva off the machine to avoid the risk of infusing clotted blood back to her. Having an override mode, in which the strict coordination done by the machine is overridden, could have helped in this situation. An example of a trade-off between the overall user experience and safety is that, though having opaque lines such that the patient cannot see their blood during treatment could be desired, having transparent lines through which they can see their blood can alert them to some problems and hence contribute to safety. Some strategies show how patients may prioritise values that can be associated with the overall user experience, like peacefulness or comfort, e.g. when they decrease the volume levels of alarms, or dialyse in an atypical place such as a verandah. This implies that improving the patient experience is also a matter of designing HHT such that patients can easily pursue such preferences.

Moreover, the discussion of Bligård & Andersson (2009) shows that there can be trade-offs between learnability and usability. They found that a newer dialysis machine with a higher level of automation than an older one was easier for participants to learn how to operate. However, the fact that participants had to learn less meant that they had less knowledge of the machine and of the treatment, and this made the newer machine harder to use than the older one in situations of extraordinary use.

14.5 Coping with the complexity of HH

HH can be seen as being complex in five different dimensions: medical, technical, social, cognitive, and physical. HH is medically complex. For example, the dry weight of a patient can fluctuate, making it harder for the patient to assess how much fluid to remove during dialysis. Also, it involves carefully balancing several aspects of a patient's physiology, especially if they have other conditions, e.g. maintaining cardiovascular stability and maintaining bone composition. HH involves technically complex procedures both related to the patient, e.g. self-cannulation, and related to the use of the technology, e.g. programming the treatment on the machine and setting up the circuit. It also involves other technical operations, such as checking water quality and disinfecting drainage lines. HH also brings a sort of social complexity. It intrudes into the lives of patients and carers, and consumes a significant amount of their time. It comes with a social burden, e.g. a carer may have a full-time job on top of their caring duties. It also involves psychosocial factors, such as relationships between patients and carers, and between patients and clinicians. HH is cognitively complex, as it requires many things to be done and to be remembered. HH is physically complex in the sense that there are several physical artefacts that need to be used or coordinated during treatment, and moreover these take up considerable space in the home environment. Also, if a patient has a fistula as their dialysis access point, they need to carefully manage the physical position of their arm during dialysis.

As aptly stated by Piccoli et al. (2005), "nothing is trivial in home hemodialysis." Given that HH is so complex, an important aspect of improving the patient experience is helping them to cope with this complexity. Some aspects of HHT design help achieve this, e.g. when it coordinates some phases of the treatment and reminds the patient of the steps, or when it provides representations that support the patient when they need to coordinate some phase of the treatment themselves. Another example is when the interface design minimises the need for a mediating artefact, e.g. when the interface provides suggestions for how to deal with an alarm such that the patient does not need to consult the manual.

There is potential to improve the patient experience by helping patients cope with the complexity of HH, through the design, deployment or use of HHT. For example, additional cues could be provided to help patients remember to perform steps for phases of the treatment that they need to coordinate themselves. An example would be having a physical placeholder into which the patient positions the items they need to use during dialysis, so they do not forget to lay out and consequently forget to inject the anticoagulant, a problem faced by Adam. Another example would be HHT providing a cue to the patient to let them know that treatment will finish soon, so they can start getting ready for take-off, instead of them having to program a separate timer, as done by Alex.

The design of HHT could also improve the patient experience by helping them with other activities of the HHS, e.g. letting them know when the filter in the machine needs to be changed, as is the case with M5, or when the special disinfection should be done, instead of the patient having to rely on temporal routines to remember to do those. More generally, next-generation HHT could ideally play a more active role in the therapy of a patient and overlap with other activities of the HHS. For example, technology for the Monitoring Renal Disease activity (see Activity 2.2 in Table 6.2) or the Lifestyle Management activity (see Activity 2.6 in Table 6.2) could be integrated with HHT.

14.6 An affair of systems and trade-offs

The patient experience, in the context of interactions with HHT, is an affair of systems and trade-offs. It is an affair of systems since, as shown in previous sections, actors, artefacts, and practices from different systems influence how patients learn to use HHT, contribute to or undermine safety during dialysis, determine the usability of HHT, and are involved in the complexity of HH. Future HHT should be designed in consideration of these broader systems.

The patient experience is a matter of trade-offs, as improving the patient experience in some cases involves finding the right balance between learnability, safety, usability, and reducing complexity. One may be inclined to assert that safety should always override all other considerations. However, in the beginning of this research, it was found that in a setting such as palliative care, it may be more important for a patient to pass away in a peaceful environment than being absolutely safe, by having a low alarm volume level on their syringe pump that is discreet but risks not being heard, instead of a high volume level that will be heard but can disrupt the peace. Though the same does not necessarily apply for renal patients, future work should focus on understanding how renal patients prioritise the different aspects of their experience, so that in cases where trade-offs have to be made in HHT design, better informed, patient-centred decisions can be made. CFA, presented in the last chapter, can help structure analysis to understand the trade-offs being made in interactions.

14.7 Summary of this chapter

This chapter discussed the patient experience of interacting with HHT in terms of four aspects: learning to use HHT, safety during dialysis, usability of HHT, and coping with the complexity of HH. Some existing design features of HHT that contribute to a positive patient experience were highlighted, and some recommendations that could potentially improve the patient experience were made. This chapter also highlighted that the patient experience of interacting with HHT is an affair of systems, and sometimes involves trade-offs amongst these four aspects. The next chapter reflects on the approach through which DCog was applied in this research to understand the patient experience of interacting with HHT.

Chapter 15: From a System of Representations to Systems of Activity-Centric Interactions

15.1 Introduction

In this chapter, I articulate the approach through which I applied DCog to study patients' interactions with HHT. As discussed in Chapter 2, there is a clear distinction between DCog and DiCoT. DCog is a theoretical framework, while DiCoT is a methodology that applies this theory in a structured way. The structure is provided mainly in terms of different models, e.g. of information flows, physical layouts, and artefacts, and the principles associated with these models. Though researchers have applied DCog in different ways, the differences lie in the *application* of the theory. The underlying theory, that cognitive processes are distributed, and that one should take a system as the unit of analysis and study how representations propagate in that system, fundamentally remains the same.

DiCoT was originally developed in a control room setting, which has different properties to a setting such as HH. The approach discussed in this chapter augments the way of applying DCog through DiCoT described in Furniss & Blandford (2006), to suit a setting such as HH. There are two main aspects to this approach: considering the setting in terms of systems of activities instead of a single system; and understanding broader interactions on top of understanding the flow of functional representations. I touched upon the first aspect in the System Activities analysis in Chapter 6. Here, I discuss the rationale for the approach in depth, revisiting some of the findings presented in earlier chapters to illustrate examples. This approach builds on the work of Rajkomar & Blandford (2012), in which an ICU setting was conceptualized in terms of a system of activities. I also revisit some findings of that study. Note that, as discussed later in this chapter, though this approach frames the setting being studied in terms of activities, it does not build on AT (Kaptelinin & Nardi, 2006) in its current scope. Together with the analysis presented in chapter 6, this approach fulfils the first contribution of this thesis, of developing an approach for applying DCog to understand situated interactions in HH. Sections 15.2 to 15.5 focus on this contribution. Then, section 15.6 discusses the utility of DCog for studying situated interactions with a HMD such as HHT. Together with the analysis presented in chapters 7-12, this discussion fulfils the third contribution of this thesis, of assessing whether a DCog approach can facilitate the understanding of patients' situated interactions with HHT. Finally, section 15.7 reflects on how the approach used in this study could be applied in other settings.

15.2 Overview of approach of applying DCog in this research

The approach described in this chapter augments DCog analysis to study activity-centric interactions within a system of systems, instead of being limited to understanding the flow of functional representations within a system. There are three main points that led me to use this approach. Firstly, because of the research question, of understanding interactions from a safety perspective, the broader system in which patients interact with HHT was of interest, as that can help understand how safety is achieved or compromised. Secondly, DCog has the potential to facilitate the understanding of more general interaction strategies and issues, besides helping to understand the flow and manipulation of functional representations. Thirdly, the nature of the HH setting is such that it is best considered in terms of a system of systems, within which there are distinct activities that fulfil system sub-goals, than to consider it as one system delineated by the flow of functional representations. These three points lead to thinking about the setting in terms of systems of activities, and then applying the DCog principles summarized in DiCoT to understand both the flow of functional representations and broader interactions in one activity of interest, the Dialysis activity in this case, and how other activities influence that activity.

The process of doing the DCog analysis thus becomes to define the system of interest, in this case the HHS, then to define the different activities within that system, and then to map out the tasks and flows of functional representations for the primary activity of interest, in this case the Dialysis activity, to determine the scope of that activity. Then, DCog principles, such as those summarised in DiCoT, can be applied to observed phenomena to identify interaction strategies and issues.

15.3 From a System to Systems of Activities

In this section I focus on the first aspect of the approach, concerning the unit of analysis, which is moving from a system to systems of activities.

15.3.1 The system of representations as the unit of analysis

Based on the definition of DCog, the way to define a DCog system is to define a system goal, based on the research question, then to look for all the processes that participate in the fulfilment of that goal: these processes form the scope of the DCog system. Typically, the DCog system thus defined and its goal map to one particular activity of interest. That is, there is a one-to-one mapping between system of interest and activity performed in that system. Or, it is at least reasonable to ignore other activities that may happen in the system. By activity I mean a set of functionally related processes or tasks that are accomplished to achieve an outcome. For example, in the study of Furniss & Blandford (2006) on ambulance dispatch, the system goal was to ensure that an ambulance is dispatched to the required location. In that case, it was possible to conceptualise the system as one set of functionally related processes, that is, a single activity, of ambulance dispatch. This is reflected in the Information Flow model that they present – all the processes of their system of interest are represented together. Essentially, in such a setting, it is possible for a researcher to define a system goal and a DCog system such that these map to one single activity. Then, the researcher can focus on understanding the flow and manipulation of representations within that activity to understand how the system goal is achieved and to identify any bottlenecks.

15.3.2 A hospital healthcare setting: a system of activities

In contrast, in a hospital healthcare setting such as an ICU, it is not possible to define a DCog system solely in terms of one activity, especially when we want to consider safety in the context of broader interactions. This is because such a setting has an overall high-level goal, and then several distinct activities are performed in that setting, with each activity fulfilling a sub-goal of that overall goal. The setting is dynamic, and these activities can happen concurrently. For example, when providing intensive care to a patient, the activity of administering an infusion can happen concurrently with the activity of patient monitoring, by either a single nurse or a team of nurses (Rajkomar & Blandford, 2012). Both activities are essential to fulfilling the overall goal of providing intensive care to the patient, but they consist of functionally different processes, and are therefore best seen as distinct activities. One may then think of just isolating the activity that relates to the research question, as a system on its own, and consider only the flow of representations within that activity. The issue is that, though the different activities have functionally different processes, they may influence each other. Their processes may overlap at some points (e.g. cross-traffic of functional representations), or one activity may change the environment in which another activity happens. As an example, in Rajkomar & Blandford (2012), the activity of infusion administration could have been reported as a system of representations on its own, as the research aim was to understand nurses' interactions with infusion pumps. However, it was found that the processes of that activity could overlap, for example, with those of the activity of patient monitoring, e.g. when the nurse detects a decline in a vital sign and decides to adjust an infusion accordingly. Another example is that the activity of serving meals to a patient can affect the activity of infusion administration, when e.g. a trolley of food positioned next to the bed blocks a nurse's line of sight to the infusion station.

Since the different activities consist of functionally different but potentially overlapping processes, and they all contribute to the fulfilment of the same overall goal, it is best to conceptualise the setting as a system of activities. A high-level system goal can be defined, e.g. providing intensive care to a patient, then the different activities that fulfil this goal can be identified, and then the focus of the DCog analysis can be directed to the activity which is of most interest, depending on the research question, while maintaining an awareness of influences from the other activities. Though several studies in the healthcare domain have used DCog as a theoretical framework, as discussed in Chapter 2, the authors do not report how they framed their unit of analysis or what the boundaries of their system of interest were. The approach of framing the setting as a system of activities makes the articulation of the scope of the analysis easier. Also, it is worth highlighting that the rationale for considering the activities within the system as being distinct from each other is that they involve functionally different processes. To illustrate, the function of the infusion administration activity in the ICU is to administer the required drug at the required concentration to the correct patient, and this involves certain processes. The function of the patient monitoring activity is to monitor the state of the patient, e.g. using the vital signs monitor, to be able to react to changes in the patient's state, and this involves a set of processes distinct from those of infusion administration. But, as mentioned, they both serve the same overall goal of providing intensive care to the patient, and their processes overlap at some points. Hutchins (1995, p. 189) mentions that "parallel activities" happen during ship navigation; however, the activities he refers to basically involve different team members concurrently manipulating and propagating representations within the same system of functionally related representations. Therefore, these "parallel activities" point to a single activity as per my use of the term activity in this discussion.

15.3.3 A home healthcare setting: a system of systems

As we move from a healthcare setting to a home healthcare setting such as HH, besides observing influences from other activities of the HHS on the primary activity of interest, i.e. the Dialysis activity, we observe influences from activities of other systems on that activity. As discussed in Chapter 6, these other systems are the HS, the DUS, and the SS. Therefore, it is best to consider the setting in terms of systems of activities. To improve the design of HMDs, it is important to understand their use in the context of the home environment. A strength of this approach to doing the DCog analysis, i.e. of defining a HHS and a HS, is that it allows for a clear articulation of the interplay between the patient's treatment, using the device, and the broader home environment. This is reflected in the interaction strategies and issues discussed in Chapter 6, e.g. how a patient adjusts his dialysis time so as to not disrupt the sleep of his young son, or how the use of high-pressure water elsewhere in the home disrupts a patient's dialysis.

15.4 From Representations to Interactions

In this section I focus on the second aspect of the approach, which is moving from functional representations to broader interactions.

15.4.1 DCog's power of representations

The main power of DCog lies in the way it prompts a researcher to look for processes involved in the traffic and manipulation of representations that contribute to a system goal, which may be outside the individual. The focus on representations and how they propagate through the system forms the foundation of DCog analyses, and leads a researcher to insights on how system design could be improved, from the low-level understanding gained on how the system currently functions. However, DCog has broader potential for informing the design of socio-technical systems; by applying DCog principles such as those summarized in DiCoT to observed activity, it is possible to abstract away from the level of functional representations to look at broader interactions. In the next sections, I distinguish between functional and affordance representations that are used in healthcare teamwork, and then show how we can apply DCog principles such as those summarised in DiCoT to understand the use of both types of representations to inform system design in terms of broader interactions.

15.4.2 Representations in healthcare teamwork

If we look at a healthcare team as a distributed cognitive system, two types of representations that are used in performing work are: functional representations, and affordance representations. By a functional representation, I refer to a representation that is directly involved in the fulfilment of the goal of the activity. It is typically manipulated/transformed by agents and may be propagated through the system. A DCog analysis typically focuses on such representations. By an affordance representation, I refer to a representation that is not directly linked to the fulfilment of the goal of the activity, but is used by an actor to facilitate the manipulation of a functional representation. That is, it affords the processing of the functional representation. It does not propagate through the system.

To illustrate, I consider an example where a nurse in an ICU is about to measure the volume of a drug that was infused to a patient in the last hour, and record this onto the Electronic Patient Record (EPR) (Rajkomar & Blandford, 2012). Several drugs are being administered to the patient, and these are listed in a certain order on the EPR. The drugs are being dispensed by several pumps stacked on a rack. Therefore, the nurse needs to identify which pump is administering which drug to the patient, measure the volume infused by that pump, then record this in the drug's corresponding entry on the EPR. Let us assume that, to facilitate this task, the nurse has arranged the pumps on the stack in the same order as the corresponding drugs are listed in the EPR, so that there is a natural mapping between the two. In this scenario, the functional representation is the volume of drug infused in the last hour. This representation propagates from the pump, to the nurse, to the EPR, and then to other clinicians who will access this information later on. This representation is important in the activity of infusion administration, as it helps the clinical team track that the intended volume of a drug is being dispensed to the patient (and not an overdose, or an underdose). The affordance representation is the physical arrangement of the pumps in the rack. It is not functionally essential, as a nurse could still measure the volume infused even if there was no natural mapping between the order of drugs on the EPR and the order of pumps on the rack, but it facilitates the work of the nurse in accessing the representation that is functionally important.

In the last example, the affordance representation involves a spatial distribution of cognition. An affordance representation can also be socially distributed. For example, let us consider a scenario where a nurse is about to press start for an infusion on a pump, and a colleague comes over to informally chat with her. While chatting, her colleague spots that something is wrong with the rate she entered for the infusion, and alerts her to it. The functional representation is the rate of the infusion, and it propagates from the nurse to the pump. The affordance representation is the other nurse, and more precisely, the knowledge inside her (if the double-checking from the other nurse was part of the formal procedure, then the other nurse would not be considered an affordance representation, but would be part of the flow of functional representations). Note that, in this case, the affordance representation is not deliberately arranged by the nurse, but is afforded by the broader system.

15.4.3 From representations to interactions

Both types of representations, i.e. functional representations and affordance representations, constitute distributed cognition. While the first type is an integral part of the core definition of DCog, the second type has not been explicitly articulated in the literature as being within the remit of DCog, though it has been implicitly referred to as constituting DCog. The reason I draw a distinction between these two types of representations here is twofold. Firstly, in a safety-critical setting, it is important to understand affordance representations as well as functional representations, as affordance representations may help understand how safety is compromised or achieved. An example of a finding in which an affordance representation is involved in achieving safety is how Adam relies on seeing his anticoagulant bottle on his table to remember to inject it into the circuit before starting dialysis. The spatial position of the anticoagulant, that is it being on the table and in his line of sight, is an affordance representation that he uses to help him remember to perform the essential function of injecting the anticoagulant. Secondly, this distinction between the two types of representations points to a broader application of DCog to inform system design, as we abstract away from representations to *interactions*, which encompasses the manipulation and flow of functional representations, the use of affordance representations, and other actions performed by actors that may not easily be mapped to representations but are important in the activity. This can be achieved if DCog principles, e.g. those summarised in DiCoT, are applied to analyse activity without being limited to the flow of functional representations. For example, while the principles in the Information Flow Model tend to focus on the flow of functional representations, the principles in the other models, e.g. Physical Naturalness, help to identify strategies and issues related to the use of affordance representations.

An important element that determines how and to what extent a DCog analysis is conducted is the questions the researcher is asking (Rogers, 2012). In this research, since the focus is on understanding patients' situated interactions with HHT, what is of interest is not only the flow and processing of functional representations, but also broader interactions between agents and the social and physical contexts in which these interactions happen. Therefore, I apply the DiCoT principles to analyse interactions within the Dialysis activity, including both the manipulation and flow of functional representations and the use of affordance representations by actors, to identify interaction strategies and issues. Note that, when applying the principles, as in Chapters 7 to 12, I abstract away from representations to interactions, and do not differentiate between functional and affordance representations. It is not necessary to do so in practice, and indeed, the distinction between the two can be blurred in some cases. I do so in this chapter only to draw attention to the broader potential that DCog has in informing system design, and to the importance of applying DCog more broadly when the setting is a safety-critical one.

15.5 From a System of Representations to Systems of Activity-centric Interactions

In this section, I discuss the combined approach of analysing interactions in systems of activities, outline the process involved in this approach, and reflect on the practical strengths of this approach.

15.5.1 Inter-activity influences at the interaction level

Previously, I discussed how activities can influence each other at the level of functional representations, when e.g. a change in a patient's vital sign leads a nurse to adjust an infusion to the patient. Activities can also influence each other at the interaction level, when for example one activity affects an affordance representation used in another activity. To illustrate this, I revisit the example of the food trolley obstructing the nurse's line of sight to the infusion pump. The nurse had initially adjusted the angle of the pump rack, creating an affordance representation, so she could see the display of an infusion pump from where she was standing. However, later on, another nurse brought a food trolley and parked it next to the patient's bed such that it obstructed the first nurse's line of sight to the pump display, hence hampering the use of the affordance representation.

In the last example, both activities, infusion administration and serving meals, belong to the same overall system, of providing intensive care to a patient. In the case of HH, we see influences among activities of different systems, both at the level of functional representations and at the level of interactions. Let us consider the example of someone showering, an activity of the HS, while a patient is dialysing. If the pressure of the water reaching the dialysis machine gets too low, the machine will start alarming. A functional representation of the other person showering needs to flow to the patient, so that he/she understands the cause of the alarm and can remedy it. To illustrate an influence at the level of interactions, let us revisit the example of Adam using the spatial positioning of the anticoagulant bottle as an affordance representation to remember to inject the anticoagulant. On one occasion, someone inadvertently placed an object in front of the anticoagulant while the patient was preparing for dialysis, and consequently he did not see it and forgot to use it. In this case, an activity of the HS hampered his use of the affordance representation. Hence, other activities and other systems can influence the activity of interest, and therefore it is important for these other activities and other systems to be reported in the analysis, especially when the setting is a safety-critical one.

15.5.2 Process of the DCog analysis through this approach

The process of doing the DCog analysis through this approach consists of defining the system of interest, in this case the HHS, then defining the different activities within that system, and then mapping out the tasks and flows of functional representations for the primary activity of interest, in this case the Dialysis activity, to determine the scope of that activity. This is captured in the tasks of the Dialysis activity, as shown in Table A.1 in Appendix A, and in the representation of the information flows involved in the Dialysis activity, as shown in Figure 7.1. DCog analyses are usually event-driven and provide descriptions of events (Rogers, 2012), rather than tasks. I add a description of tasks in my approach, as healthcare activities involve both reactive, event-driven work, and planned work. Examples of the latter are when a nurse is preparing a drug for an infusion, or when a patient is preparing their machine for dialysis. From a safety perspective, it is important to understand strategies and issues related to these procedural tasks as well. This can be achieved by applying DiCoT principles to phenomena observed during these tasks, for example highlighting the affordance representations that are used in a task.

As the analysis proceeds, though the focus of the analysis will be on the primary activity, influences from other activities and other systems can be captured, and these activities and systems can then be defined, as shown in Figures 6.2 and 6.1. Once the scope of the primary activity has been defined, we can use the DiCoT principles to analyse phenomena within that activity, to identify interaction strategies and issues. The different principles allow us to understand strategies and issues that involve people, the physical environment, artefacts, and the time continuum. An important difference of this approach from the approach of Furniss & Blandford (2006) is that, while Furniss & Blandford (2006) consider only artefacts and physical layouts involved in the processes defined in their representation of information flows, in this approach I apply the DiCoT principles to all phenomena, regardless of whether they are related to processes defined in the representation of information flows. This means that equal prominence is given to all the models, instead of the Information Flow Model acting as a filter for analyses in the other models. This allows a broad range of interaction strategies and issues to be identified. Another justification for this approach is that, as discussed in Chapter 4, this study does not look at a single instance of a system, e.g. one control room, but it looks at many instances of a system, with one instance for each patient. Each instance has its own physical and social environment, resulting in a broad range of interaction strategies and issues across participants. By applying the DiCoT principles to the phenomena observed for each participant, we can conduct a structured analysis of interaction strategies and issues across all participants.

15.5.3 A note on this approach and Activity Theory

Existing studies in the healthcare domain that used AT as a theoretical framework also structured their analysis in terms of activities (Bardram, 2009; Bardram & Doryab, 2011). This provides support to the argument that healthcare work may be best characterized as consisting of distinct activities. However, whilst such studies apply the notion of an activity in a top-down fashion, based on AT, the notion of activity emerged bottom-up in Rajkomar & Blandford (2012) as a useful way of grouping functionally related processes in the phenomena observed in the ICU. A distinction that makes this clear is that, as per AT, an activity cannot be reduced to tasks, as it needs to include, for example, the actor's motivations and the meaning the tasks bear to the actor (Kaptelinin, 2013), whereas I use the term activity to represent a set of functionally related processes, to be able to structure DCog analysis in an unstructured setting. The structuring of work in terms of activities, one of the major strengths of AT, is the only commonality between the approach presented here and AT; I do not apply AT in my analysis, and I frame activities in the context of an overarching (distributed cognitive) system goal. Future work could investigate the benefits of supplementing the DCog analysis presented in this thesis with an AT analysis. As discussed in Chapter 8, some strategies and issues arise because of patients' personal motivations, for example their values and preferences. Since AT explicitly considers the motivations of actors, it could be better suited to uncover such interaction strategies and issues.

15.5.4 Practical strengths of this approach

This approach not only facilitates the use of DiCoT principles to understand broader interactions to inform system design, but it also has some practical strengths from the perspective of an HCI researcher engaging with a complex setting such as HH. Reflecting on the application of DCog in general, one problem faced by the researcher is the definition of the boundary of the analysis (Carroll, 2003; Halverson, 2002). A setting such as HH is by its nature less structured than a control room setting or even a hospital healthcare setting, making it even more problematic for a researcher to define a system boundary and conduct a structured analysis of observed phenomena in the setting. This approach of viewing the setting in terms of systems of activities brings structure to the analysis, and helps to address the problem of defining the boundary of analysis. Also, it may not be practically possible for a lone researcher to capture all phenomena in such a setting, especially if video recording is not possible. This approach helps the researcher make sense of the complexity of the setting, and gives a focus for the analysis – after gaining an understanding of the different activities in the setting, the researcher can focus on the primary activity of interest. Finally, due to restrictions in the kind of data I could gather, I could only perform limited low-level analyses of the flow of representations between the patient and their machine, e.g. by analysing detailed representations on the machine's interface. Nevertheless, through this approach, I was able to complement observational data with interview data to identify higher-level interaction strategies and issues, by coding data with the DiCoT principles. DCog has been criticised for lacking a set of pre-existing concepts that can guide data analysis (Nardi, 1996). The DiCoT principles address this shortcoming, and can be effectively used to guide data analysis.

Typically, studies in healthcare that used DCog just mention that DCog was used, without giving any details on how it was used and what the extent of the analysis was. Another benefit of this approach is that, since it is structured, it makes transparent the scope of the analysis that was done, making eventual comparisons with other studies easier.

15.6 The utility of DCog for studying safety-critical interactions with HMDs

In this section, I discuss the utility of DCog for studying interactions with a HMD in a safety-critical setting such as HH. Due to the lack of studies focusing on understanding interactions with HMDs, there is no literature that allows for comparing and contrasting the DCog approach with other approaches such as AT. Hence, this section discusses the utility of DCog mostly based on the experience of applying it in this research, and on a reflection on the characteristics of the HH setting and how a DCog approach addresses these characteristics.

15.6.1 Home Haemodialysis as a distributed cognitive system

The results of this study show HH as a distributed cognitive system, in which processes are distributed through people, the physical environment, artefacts, and the time continuum. The information flow analysis in Chapter 7 showed at a basic level the different agents, both human and machine, that help the system achieve its overall goal of providing renal replacement therapy to a patient. The social structures analysis in Chapter 8 highlighted how processes are distributed among the patient, the carer/helper, the nephrologist, the home nurse, and the technician. The physical layouts analysis in Chapter 9 highlighted how the physical environment and space is used by patients to support their activity. The artefacts analysis in Chapter 10 highlighted the importance of different artefacts that patients use to support their activity, and also showed how processes are distributed between the patient and the machine. The temporal structures analysis in Chapter 12 highlighted how patients use the time continuum to reduce complexity in their activity.

15.6.2 Understanding a socio-technical, safety-critical, and complex system

Besides being a distributed cognitive system, HH is a *socio-technical*, *safety-critical*, and *complex system*. The DCog approach helps to address each of these different characteristics of the system. Obviously, DCog is a suitable approach for studying a setting that is best described as a *system*, as one of the core tenets of DCog is to take a system as the unit of analysis from the outset. It is suitable for studying a *socio-technical* system, as it explicitly considers the roles of both people and technology in the system; from a DCog perspective, both are seen as agents in the system. It facilitates an analysis of how roles could be distributed among people and between people and technology. Additionally, it is suitable for understanding how safety is achieved or compromised in a *safety-critical* system. Safety has been defined as a property of interconnected components of a system (Fields et al., 1999), and DCog explicitly looks at how the different components of a system work together in achieving its function. For example, the social structures analysis showed how patient safety in the Dialysis activity depends on other people such as a carer, a helper or a neighbour, who may need to intervene in an emergency. Also, the artefact analysis highlighted how safety is provided by the design of the machine, when it ensures that the patient performs the correct step.

In a *complex* system, people are likely to employ strategies to cope with complexity, and these strategies may involve distributing cognitive processes through different media (other people, physical environment, artefacts, time continuum). One aspect of the complexity of HH is that the patient needs to do many different tasks, needs to remember to do them, and needs to remember the procedures for doing them. DCog, when applied through a structured method such as DiCoT, is well suited to help understand how people cope with complexity in such a system; the different principles act as theoretical lenses that help identify strategies in which cognitive processes are distributed through people, the physical environment, artefacts, or the time continuum. By using a broad set of 26 principles to structure analysis, I was able to engage with a large number of phenomena and identify a broad range of interaction strategies and issues.

Besides helping to understand how actors of a system cope with complexity within that system, DCog also allows the researcher to engage with a complex setting. It may be daunting or practically impossible for a researcher to capture/report all phenomena during data gathering and analysis, especially when video-recording is not possible. DCog acts as a theoretical filter that allows the researcher to practically engage with the setting being studied and construct an understanding of it. Given that, typically, with a theoretical filter, some phenomena are given priority at the expense of others, one may question the suitability of DCog as a filter. I argue that the suitability of DCog for this purpose, in the context of understanding how safety is achieved or compromised in a system, comes from the fact that it focuses on understanding the very foundation on which a system is built, by looking at how information representations propagate through the system to achieve the system's function. Therefore, it appropriately directs the focus of the researcher to phenomena that are essential for the system to work as it does. This results in an understanding of the basic mechanisms involved in the system, as discussed in Furniss & Blandford (2010) and Rogers & Ellis (1994), and is especially useful when the researcher is familiarising themselves with a domain that is new to them, as was the case in this research. The basic mechanisms involved in the HH system are captured in the different DiCoT models in Chapters 6-12, through the general descriptions of typical activity.

Moreover, the DCog approach does not preclude other focuses of data gathering and analysis. A researcher is free to consider other phenomena of interest in their analysis, depending on their research question and the nature of the setting being investigated – e.g. interviewing can be extended to understand participants' affective issues. In this research, it was important to understand the different factors that influence a patient's interactions with HHT. Therefore, I enriched the analysis by considering some issues that do not fall under the remit of DCog, namely physical ergonomics, individual knowledge, and individual values and preferences, to understand a broad range of interaction issues that patients face.

15.6.3 Insights to inform system design

A DCog analysis provides insights on the basic mechanisms that make the system work, as described above, but also insights on current issues in the system, which can help inform system design (Furniss & Blandford, 2010; Rogers & Ellis, 1994). In this research, the analyses through the different DiCoT models pointed to safety-related interaction design issues and potential design improvements. The following are some examples discussed in previous chapters:

- The information flows analysis in Chapter 7 highlighted the importance of having a communication channel between the patient and the carer during dialysis, especially when the carer is in other parts of the home during dialysis.
- The social structures analysis in Chapter 8 showed that the interface of HHT should be designed such that an untrained person can interact with HHT in case of emergency.
- The physical layout analysis in Chapter 9 stressed the importance of patients being able to easily distinguish between different connection ends, to reduce the risk of wrong connections, which has already been fatal.
- The artefacts analysis in Chapter 10 indicated the need for the device to provide better guidance to patients on the causes and solutions of alarms.
- The temporal structures analysis in Chapter 12 highlighted that the machine could indicate to the patient when it is time to start getting ready for treatment termination, to avoid risks of haemolysis.

15.6.4 Variations in technology and practices

The technology and practices involved in HH vary over time and across hospitals and countries. Practices evolve over time, e.g. as clinicians learn from experiences of previous patients to improve the experience of future patients. Technology evolves, e.g. as manufacturers improve the design of the technology based on patients' experiences. Technology and practices also vary across hospitals and countries. For example, M3 is very different in the way it is used from the other machines. It is portable, unlike the other machines, and works with a disposable cartridge, such that the lining of the circuit is simplified. As an example of a variation in practice, in the case of H1, there is a home nurse who visits the patient on a monthly basis, whereas in the case of H3 no nurse visits the patient at home.

Despite all these variations, the system that provides HH treatment to the patient fundamentally remains a distributed cognitive system, the *configuration* of which varies with variations in technology and practices. Moreover, other types of supported home therapies are likely to be distributed cognitive systems as well. For example, Obradovich & Woods (1996), in their study on the use of infusion pumps in pre-term labour management, describe that setting as a distributed cognitive system. Even a therapy that involves only a patient and a smart medical device is a distributed cognitive system, as processes will be distributed between the patient and the device. This is the basic premise of the Distributed Information Resources Model (Wright et al., 2000), which provides a way to analyse distributed cognition in interactions between an individual and a technology, in terms of resources for action. Therefore, DCog is a useful theoretical framework for understanding interactions with HMDs such as HHT, especially when the research aims to understand how safety is achieved or compromised.

15.7 Applying this approach in other settings

The approach used in this research, of conceptualising DCog analysis in terms of systems of activity-centric interactions, could be useful for studying interactions with technology in other settings, especially if the setting is complex but loosely structured, and if the research aims to understand how the broader context influences interactions. As discussed in section 15.5.4, the value of this approach is that it would bring a clear structure to the analysis, and help the researcher to engage with the setting. Also, by applying the DiCoT principles to observed phenomena in the activity of interest, a range of interaction strategies and issues could be identified.

As described in section 15.5.2, the process of applying this approach would consist of initially defining a system of interest, based on the aims of the research, in which the user-technology interaction of interest happens. Then, as the researcher constructs an understanding of the setting, a primary activity can be defined, in which the interaction of interest happens. The tasks and flows of functional representations involved in this activity could be mapped out, to determine the scope of this activity. As the analysis proceeds, though the focus of the analysis would be on this primary activity, influences from other activities and other systems could be captured, and these activities and systems could then be defined. Once the scope of the primary activity has been defined, the DiCoT principles could be used to analyse observed phenomena within that activity, to identify interaction strategies and issues. The different principles facilitate the understanding of strategies and issues that involve people, the physical environment, artefacts, and the time continuum. This allows a range of interaction strategies and issues with the technology of interest to be identified, spanning the broader context in which interactions happen. If the research also aims to understand how the technology of interest could potentially support work in the secondary activities defined, then these activities could be studied in more detail, to gain a deeper understanding of how representations currently flow between them and the primary activity.

15.8 Summary of this chapter

In this chapter, I discussed the approach through which I applied DCog to understand patients' strategies and issues when interacting with HHT. The approach consists of conceptualizing the HH setting in terms of systems of activities, and of abstracting away from functional representations that propagate in the distributed cognitive system to broader interactions that happen during activity. In this way, as shown in chapters 6-12, a broad range of interaction strategies and issues can be identified, related to people, the physical environment, artefacts, and the time continuum. These can lead to insights to inform system design. HH is a complex, safety-critical and socio-technical system, and DCog effectively helps to address these different characteristics of the system. Though HHT and practices may vary, the system that provides treatment to a patient essentially remains a distributed cognitive system. This posits DCog as a useful theoretical framework for understanding situated interactions with HMDs such as HHT.

The work presented in this chapter draws upon work done for my MSc thesis, which has been published as:

Rajkomar, A., & Blandford, A. (2012). Understanding infusion administration in the ICU through Distributed Cognition. *Journal of biomedical informatics*, *45*(3), 580–90.

Chapter 16: Conclusions & Future Work

16.1 Conclusions

This research sought to understand a broad range of strategies and issues that renal patients have when interacting with HHT, to inform the design of HHT. It is different from the few previous studies that looked at interactions with HMDs mainly in that it explicitly uses DCog as a theoretical framework to guide analysis, and that it presents a broad range of interaction strategies and issues across the themes of: system activities, information flows, social structures, physical layouts, artefacts, system evolution and temporal structures.

The results show that DCog is a useful theoretical framework for understanding situated interactions in a safety-critical setting such as HH. The representational models of DiCoT help to understand the context of interactions, and the principles summarized in DiCoT act as theoretical lenses that guide analysis and facilitate the identification of strategies and issues that pertain to different forms of distributed cognition.

Two gaps were identified in the principles, given the focus of this research on understanding interaction strategies and safety. Firstly, some identified strategies leverage forms of temporally distributed cognition not addressed in the existing literature. This thesis developed some principles for understanding such strategies, namely: temporal layouts, temporal assignments to tasks; dealing with anticipated problems; distribution of a task plan; reducing peak complexity; and time for action. Secondly, because of its systemic focus, one limitation of DCog is that it does not provide lenses for understanding strategies that arise because of an individual's knowledge or because of their values and preferences. This limitation was addressed in this thesis by expanding the scope of the analysis of social structures to consider patients' individual knowledge and their individual values and preferences.

The nature of HH posed two challenges to the study of situated interactions. Firstly, the setting is unstructured, and the broader context influences patients' interactions with HHT. To address this, DCog analysis was augmented in two ways: the setting was conceptualized in terms of systems of activities instead of a single system, and the analysis considered broader interactions instead of being limited to the flow and manipulation of functional representations. Secondly, due to the complexity of the setting, some interaction strategies are complex in the sense that there are many factors related to them. Moreover, these strategies may vary from patient to patient, as there are significant variations in patients' contexts of interactions. To address this, an analytical framework of CFs was developed, to provide a mechanism for unpacking the factors related to complex strategies and for reasoning about design implications across patients' strategies.

The interaction strategies and issues identified in this research help to understand the patient experience in terms of four inter-related aspects: learning to use HHT, safety during dialysis, the usability of HHT and coping with the complexity of dialysis. The interaction strategies and issues provide insights on aspects of the design of HHT that currently contribute to a positive patient experience, and lead to recommendations that could further improve the patient experience. The patient experience in HH is an affair of systems, as several systems influence it, and a matter of trade-offs, as it involves trade-offs among the four aspects mentioned.

16.2 Future work

This research aimed to identify a broad range of interaction strategies and issues, instead of focusing on a particular aspect of HHT design. Based on the findings of this research, future work could focus on a specific aspect of HHT design. For example, CFAs could be performed with strategies relevant for a specific design aspect to make recommendations for that specific design aspect.

This research focused on applying DCog to understand situated interactions with HHT. Future work could investigate the benefits of supplementing the DCog analysis with an AT analysis. Some strategies and issues arise because of patients' personal motivations, e.g. their values and preferences. Since AT explicitly considers the motivations of actors, it could be better suited to uncover and understand such interaction strategies and issues.

This research focused on understanding interactions during the Dialysis activity. Future work could study the other activities within the HHS, to investigate if there is potential for HHT design to support patients in these other activities, for a better patient experience. Also, future work should focus on understanding how renal patients prioritise the different aspects of their experience, so that in cases where trade-offs have to be made in HHT design, patient-centred decisions can be made.

16.3 Summary of the contributions of this research

This research brings five contributions to the study of patients' situated interactions with HHT. Firstly, it provides an account of patients' experiences of interacting with HHT. Secondly, it demonstrates the utility of DCog as a theoretical framework for understanding interactions with a HMD such as HHT, especially when the research aims to understand how safety is achieved or compromised. Thirdly, it develops new theoretical principles that help to understand how people distribute cognitive processes through time. Fourthly, it develops a Contextual Factors Analysis that facilitates the analysis of complex interaction strategies to inform design. Finally, it develops an overarching approach that augments DCog analysis from considering a system of representations to considering systems of activity-centric interactions.

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Appendix A: Home Haemodialysis Background

A.1 Treatment background (based on interview with home nurse of H1)

The goal of haemodialysis is to clean the patient's blood and remove any excess fluid that the patient has. Before dialysis, the patient measures his/her current weight and compares that to his/her dry weight (a baseline weight). The target is to remove excess fluid such that, after dialysis, the patient's weight will be almost equal to the dry weight. Initially clinical staff work out an estimate of the dry weight of the patient, based on the patient's bioimpedance, and the patient is taught how to assess changes in their dry weight. The patient's dry weight changes when he/she puts on or loses weight (that is not due to fluid).

While it would be desirable to remove as much of the excess fluid as possible, the way the dialysis is done needs to be balanced with other physiological aspects of the patient. Importantly, the cardiovascular stability of the patient should be maintained, by maintaining a certain blood pressure. The blood pressure is affected by the fluid that is removed during dialysis, and by the dialysate temperature. A patient needs to adjust their dialysis parameters depending on patient-specific symptoms, which they learn to understand, and how they feel. The patient can measure their blood pressure during the dialysis session to get an idea of what's going on if they are not feeling well; the patient is taught what is their normal blood pressure. An example of a symptom is getting cramps in the last hour of dialysis. This could be an indication that either the patient is taking off too much fluid, or they got their dry weight wrong. On M1, a patient can also try setting the machine to a "Min UF" (minimum ultra-filtration) mode, which suspends fluid removal for 10 minutes, and the patient might feel better. Conversely, a symptom of a patient being fluid overloaded is puffy fingers or puffy eyes. Another thing a patient can measure if they are not feeling well is their temperature; a high temperature could indicate that they have an infection in their vascular access site. The temperature of the dialysate during dialysis needs to be carefully adjusted as well. It is typically set to slightly less than body temperature, e.g. 36.5 degrees Celsius, to avoid vasodilation, which can lead to a decrease in the patient's blood pressure and a hypotensive episode. This results in the patient feeling cold during dialysis, and to offset this, the patient may e.g. cover themselves with a blanket.

A patient also records the arterial and venous pressures that are displayed on the machine's screen during a particular session. Arterial pressure is the pressure in the line from the patient to the dialyser while venous pressure is the pressure in the line from the dialyser back to the patient. A patient knows what his/her normal arterial and venous pressures are, based on history. If, while recording the pressures on the chart and comparing them with the history, the patient sees that there has been a change in the last 2 or 3 readings, the patient should phone the nurse and tell her that the pressures are not the same any more, and she will investigate why. E.g. if the patient increased the speed of the blood pump, the pressures can be expected to increase.

On a monthly basis, there is a HH clinic, which involves either the nurse visiting a patient at home or the patient visiting the nurse in the hospital. During this clinic, the nurse assesses the patient to see if there have been any changes in the patient's blood pressure and symptoms. The nurse also collects a sample of the patient's blood that is assessed in the hospital to measure the efficacy of the patient's dialysis treatment. When the clinic happens in the hospital, the nurse also measures the patient's standing blood pressure, the infection level of the patient's vascular access site, and the patient's bioimpedance to get an idea of the patient's dry weight.

The nephrologist prescribes a specific dialysate canister, containing a certain level of calcium and potassium, for a patient depending on that patient's blood results. The doctor also prescribes a specific 'bicart', containing sodium and bicarbonate, depending on a patient's specific needs. It is desirable to have the sodium level as low as possible, but if the patient is having symptoms, then the patient can decide to increase it. So, typically the sodium setting is not programmed on the machine until it is known what works for that patient. The bicarbonate level is pre-set by the technician based on the patient's prescription. During dialysis, a patient's level of bicarbonate increases from very low to normal, correcting acidosis. The prescription for the dialysate and the sodium bicarbonate can change depending on the patient's blood results. The nephrologist also prescribes potassium and calcium levels for the patient. A patient who dialyses every day would need a higher potassium as that patient would be losing more during dialysis. Calcium is kept as low as possible for patients already having high levels of it, and increased in those having very low levels. With time, the clinicians calibrate the patient's dialysis treatment at home, which is different from their treatment at the dialysis unit; in the unit it is usually only 3 times a week, while at home more dialysis may be done, so the patient may need more potassium or less phosphate binders prescribed. Dialysis does not replace all of the functions of kidneys, and the condition of the patient deteriorates with time. Not dialysing for two days leads to build-up of toxins in the patient's body, which can be fatal. Deaths typically occur during this period.

A.2 Main risks for patient safety during dialysis

Some of the main risks for patient safety during dialysis are:

- Hypotensive episode. Patient can pass out, fall down, their needles come out, and they may die through exsanguination, which is losing their blood. This can be complicated by the patient falling asleep during dialysis.
- If a patient falls down and injures themselves, e.g. after passing out, this can lead to internal haemorrhage. Because of the anticoagulant used during dialysis, the patient's blood may not clot.
- Clotting of blood in the circuit. If blood clots in the dialysis lines, pressures can build up in the lines, forcing the needles out of the patient's access site.
- Infusing blood that has clotted in the dialysis circuit back to the patient. Clotted blood haemolyses, and this can lead to complications if infused back to the patient.
- Blood leak, e.g. if a clamp at some point in the circuit gets unclamped
- Air embolism, if the cleaned blood returning to the patient contains air bubbles

A.3 Tasks within the Dialysis activity

Table A.1: Tasks within the Dialysis activity

TASK	SUMMARY
1. Wipe machine and surfaces	The patient wipes the outside of the machine and other surfaces used during dialysis, e.g. table or tray, with a disinfectant, to prevent infections.
2. Start auto-disinfection on machine	The patient activates the different components of the TS, which involves switching on the water supply to the water purifier, by turning a lever, switching on the water purifier, and switching on the dialysis machine. The patient starts an auto-disinfection process on the machine, which disinfects the machine internally. This takes about 50 minutes.
3. Gather items for starting treatment	The patient collects medical supplies, such as syringes, plasters, wound dressings and needles, and places these on a tray. This tray will be used mostly when the patient is connecting/disconnecting themselves to/from the machine. The patient also collects disposable dialysis supplies that are needed to form the dialysis circuit, such as the dialyser, the lines, the saline bag, the acid canister, and the bicarbonate cartridge.
4. Pre-dialysis measurements	The patient measures their weight and compares this to their dry weight to know how much fluid needs to be removed during the dialysis. The patient also measures their blood pressure, pulse and temperature. These measurements are recorded in a dialysis chart.
5. Connect acid and bicarbonate to machine	When the auto-disinfection process on the machine has finished, the patient selects the required concentration for their dialysate solution, and then connects an acid canister and a bicarbonate cartridge to the machine. The machine then mixes these two with ultra-purified water from the water treatment unit to form the dialysate solution at the required concentration, and performs some checks. In the case of M3, the patient needs to have prepared a batch of dialysate through the machine beforehand, which takes 7.5 hours.
6. Line circuit for priming	This involves placing two sets of tubes, color-coded red and blue, on designated areas on the machine to form a circuit. Initially, the red line is connected to a saline bag and to the dialyser, while the blue line is connected to an empty bag and to the dialyser. This forms a circuit for priming the line with saline. The lining is simplified with M3, as it uses a cartridge on which the different components are already mounted.
7. Start priming	The patient starts the priming process on the machine, which circulates saline in the circuit and removes air bubbles. The machine also performs some other self-tests. With M5, which supports haemodiafiltration, water is used for the priming instead of saline.
8. Insert needles/lines into patient's access site	If the patient's access site is a fistula, the patient pricks their fistula with two needles. Some patients then use a syringe connected to the needle to draw blood from the access and then push the blood back, to test whether blood is flowing properly through the access. The blood may not flow properly if e.g. the needle is touching the wall of their vein, and the patient may then adjust the position of their needles. If the patient has a catheter access, e.g. into their neck, they connect two lines to the catheter. Then they use a syringe to extract the anticoagulant that they inserted into the line after the last dialysis session to prevent clotting inside the line. Then they connect another syringe filled with saline to the line, and push and pull the saline to check that the line is flowing properly and there are no clots in it.
9. Re-route circuit to connect to patient	The patient disconnects the red and blue lines from the saline bag and the empty bag and connects them to the needles at their access site. The circuit now runs from the patient's access site to the dialyser, which is the "arterial line", and back from the dialyser to the access site, which is the "venous line".
10. Inject anticoagulant	The patient then injects an anticoagulant into the circuit, e.g. tinzaparin, to prevent blood from clotting in the circuit during dialysis.

11. Program parameters	The patient enters the desired duration of the treatment in hours and the volume of fluid that they want removed, the Ultra-Filtration (UF) volume. UF volume = Measured Weight – Dry Weight + Washback (extra fluid due to saline used for rinsing back at the end of treatment) + Drink during dialysis. E.g. for Gina: UF volume = 0.5 Excess Weight + 0.2L Washback + 0.2L Tea = 0.9 litres. Some patients may also need to change the default parameter for the level of sodium in the dialysate, if their hospital does sodium-profiling. This is usually pre-set by the technician to a default value prescribed by the nephrologist for a particular patient, but depending on fluctuations of the patient's post-dialysis blood pressure, the nephrologist may request the patient to change it to a higher value. Some other settings, such as the temperature of the dialysate and other properties of the dialysate, are pre-set by the technician and the patient does not usually need to change them. M3 works differently, in terms of the volume of dialysate to be used in a session. This is pre-set, and the patient sets the volume of fluid to be removed and blood pump speed. With M5, the patient can specify a profile for the treatment, which determines whether fluid is removed from their blood at a constant rate or at varying rates through the session.
12. Start session	The patient presses a button on the machine's interface to start the programmed session. During dialysis, the patient's blood and the dialysate solution flow counter to each other in the dialyser, and wastes, nutrients and fluid are exchanged between the two through diffusion and osmosis. After starting the session, the patient reads the pressures in the arterial and venous lines to see if they are within a reasonable range as a confirmation that the blood flow has been properly established, and that e.g. they have not forgotten to unclamp part of the line, in which case the venous pressure would be abnormally high. Some patients may need to inject some drugs, e.g. erythropoietin or iron, into the line running back to them at this point. Some patients start with a low blood pump speed and then gradually increase it, as they assess the stability of the pressures in the lines, until they reach an optimal pump speed which gives them best dialysis, with the pressures in the lines within the safety limits. If the needles were not positioned optimally, and therefore the pressures in the lines are not optimal, the patient may have to use a lower blood pump speed and compensate by dialysing for longer.
13. Take physiological and machine readings	After starting dialysis, the patient again records his blood pressure, pulse, and temperature. Checking the temperature is important for patients with a catheter access, as it is more prone to infections, and an abnormally high temperature could mean they have an infection. Some patients check these readings every hour during dialysis. At some point during the session, the patient also records the arterial and venous pressures in the dialysis chart, for the nurse's future reference. Some patients record these hourly, together with the other physiological readings.
14. Attending to machine alarms and patient symptoms	Throughout the session, the patient attends to any alarms from the machine. Some typical alarms are: • venous pressure alarm, when the pressure in the venous line goes outside of the set safety limits • arterial pressure alarm, when the pressure in the arterial line goes outside of the set safety limits • low water pressure alarm, when the pressure of water from the water treatment unit to the machine is not high enough • air alarm, when the machine detects air bubbles in the circuit In case a patient cannot solve an alarm, even with the support of a nurse or technician over the phone, they have to abandon that session, disconnect themselves from the circuit and lose the blood currently in the circuit. For example, in case of an air bubble alarm, if they cannot figure

	out where the air is, or if there is too much air in the circuit, they have no choice but to abandon the session, to avoid any risk of air embolism. The patient may need to take some measures if they suffer from symptoms. E.g. if they are having a hypotensive episode, i.e. their blood pressure is lowering, and they feel they may pass out, they may administer some saline to themselves through the circuit, or drink something, or call for help from their carer/helper. This is one of the main safety risks during dialysis. Fatal incidents have occurred when a patient passed out due to hypotension and they fell down; their needle came out of their access site, and they exsanguinated to death.
15. Gathering items for terminating treatment	If a patient has not already gathered the items they will need when coming off the machine, e.g. wound dressings and drugs, they do so towards the end of the session.
16. Inject drugs	Some patients need to inject drugs such as erythropoietin or iron through a syringe into the circuit towards the end of the treatment. Some patients may also inject some saline into the circuit, to help alleviate symptoms of low blood pressure.
17. Re-route circuit for washback	At the end of the treatment, the patient disconnects the red line from their access site and connects it to the saline bag.
18. Start washback	The patient starts the "washback", in which saline is dispensed to rinse the blood remaining in the circuit back into the patient. Then the patient disconnects their needles from the lines.
19. Start termination process on machine	The patient follows prompts on the machine's interface to let the machine perform some termination steps, e.g. draining the dialyser.
20. Attend to patient's wound	The patient attends to their wound if they have a fistula, e.g. putting a dressing on it and pressing it until bleeding stops. The bleeding can take a variable amount of time to stop, e.g. Felix sometimes has to wait up to 45 mins.
21. Post-dialysis measurements	The patient measures their weight, blood pressure and pulse, and reads how many litres of blood were processed and how much fluid was removed from their blood from the machine, and records all these in the dialysis chart.
22. Start auto-disinfection on machine	The patient starts an auto-disinfection process on the machine.
23. Remove and dispose of lines	The patient removes the lines from the machine and disposes of them into a clinical waste bin. They also wipe the outside of the machine with a disinfectant.

Appendix B: General Methodology

B.1 Participant Information Sheet for patients

REF: WP4/AR/1.0(HOME): InfoS_Patient_v2 [18.04.11]

(name of Trust)
(address)
(telephone)

Patient Information Sheet - Medical Device Study

We invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One member of our team will go through the information sheet with you and answer any questions you have. This should take about 10 minutes.
Part 1 tells you the purpose of the study and what will happen to you if you take part.
Part 2 gives you more detailed information about the conduct of the study.
Talk to others about the study if you wish. Ask us if there is anything that is not clear.

Part 1

What is the purpose of the study? The purpose of this study is to investigate the design and use of interactive medical devices, namely dialysis machines, infusion pumps, and vital signs monitors, in contexts outside the hospital, such as homes and hospices. This involves medical device use by patients. We would like your help to identify what is good, bad and what could be improved in terms of medical devices. For example, would you make any changes to medical devices so they were easier to use? We would like to hear your views and opinions on the medical devices you use. However, please do not feel under any pressure to agree. This study is being undertaken for educational purposes, as part of the researcher's PhD degree.

Do I have to take part? It is up to you to decide to join the study - your participation is completely voluntary. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving reason.

What will happen to me if I take part?

- We would like to observe your interaction with the device, in the way that you naturally use the device.
- We would like to interview you about your experiences with the device. The interview will last about 30 mins. We will explicitly ask permission to audio-record the interview. The audio recording will be destroyed once it has been transcribed.
- If we need to take pictures of the device, we will explicitly ask permission to do so.
- If you are willing to, we will request you to keep a diary of minor incidents and issues you face while interacting with the device, and will loan you video equipment to support the capturing of incidents, at your own discretion and convenience. We will then arrange for a short follow-up interview.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. Detailed information concerning this is given in Part 2 of this information sheet.

Part 2

This study is interested in the design and use of medical devices, and is run by University College London. Details of the study are explained below:

I. Purpose of the investigation - This study aims to investigate the design and use of medical devices in contexts outside the hospital, such as homes and hospices. This involves medical device use by patients. We would like your help to identify what you think is good, bad and what could be improved in terms of medical devices and patient care. For example, would you make any changes to them so they were improved for another patient?
II. Risks and benefits – This study does not change any aspect of the care given to patients, instead the study involves observing what already happens and talking to people about their opinions and experiences. We cannot promise the study will help you directly but the information we get will help improve the treatment of people in the future.
III. Voluntary participation - Your participation is completely voluntary. You have the right to withdraw from the investigation at any time, and can decline to answer any question, without giving reason.
IV. Confidentiality - All information will be treated confidentially, except in cases where patient safety is the overriding concern. A report may be written, and papers may be published, but no names will be associated with the data. All data, including hand-written notes, photographs, audio, video, and diaries, will be anonymised in any analysis and write-up of the work.
V. Problems, concerns and complaints – Every care will be taken in the course of this study. However, in the unlikely event that you are injured by taking part, compensation may be available. If you suspect that the injury is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with your research doctor, please make the claim in writing to Professor Ann Blandford who is the Chief Investigator for the research and is based at University College London Interaction Centre. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff or about any side effects (adverse events) you may have experienced due to your participation in the research, the normal National Health Service complaints mechanisms are available to you. Please ask your research doctor if you would like more information on this. Details can also be obtained from the Department of Health website: http://www.dh.gov.uk .
VI. Who has reviewed the study? This study has been reviewed by the West London REC 2 Research Ethics Proportionate Review Sub-Committee, to protect your interests.

Researcher's contact details: Atish Rajkomar, 0207 679 0363, atish.rajkomar.09@ucl.ac.uk

B.2 Consent Form for patients

WP4/AR/1.0(HOME): Consent_Patient_v2 [18.04.11]

(name of Trust)
(address)
(telephone)

Patient Consent Form - Medical Device Study

Study Reference: WP4/AR/1.0(HOME)
REC reference number: ?
Patient Identification Number:
Title of Project: **Medical Device Design and Use in the Home**
Name of Researcher: Atish Rajkomar

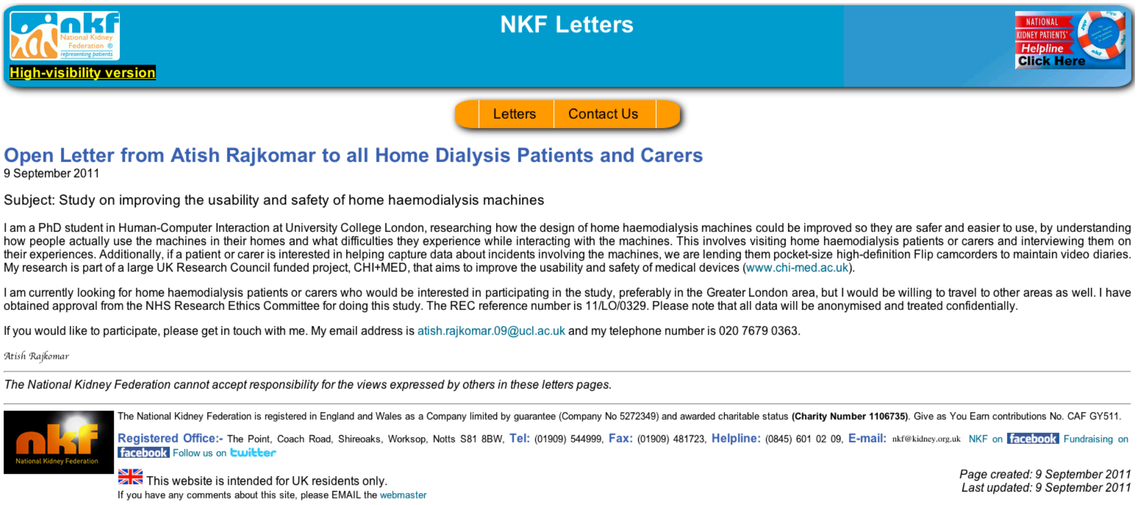
	Please initial box to confirm
1. I confirm that I have read and understood the information sheet dated 18.04.11 (version WP4/AR/1.0(HOME): InfoS_Patient_v2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
3. I understand that all observations and discussions will remain confidential except in cases where patient safety is the overriding concern. I understand that my name will not be associated with any subsequent reports related to the study.	
4. I understand that the researcher will ask permission before taking pictures of the medical devices. I understand that I can decline this request.	
5. I understand that if I am asked to take part in an interview the researcher will ask permission that it is audio recorded. I understand that I can decline this request.	
6. I understand that the researcher may invite me to keep a diary of incidents with the medical devices, and may invite me to video-record incidents using loaned equipment. I understand that I can decline these invitations.	
7. I agree to take part in the above study	

Name of Patient_________________________ Date____________ Signature_________________

Name of Person_________________________ Date____________ Signature_________________
Taking Consent

When complete: 1 copy for participant; 1 (original) for researcher for filing

B.3 Open letter on National Kidney Federation website



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Open Letter from Atish Rajkomar to all Home Dialysis Patients and Carers
9 September 2011

Subject: Study on improving the usability and safety of home haemodialysis machines

I am a PhD student in Human-Computer Interaction at University College London, researching how the design of home haemodialysis machines could be improved so they are safer and easier to use, by understanding how people actually use the machines in their homes and what difficulties they experience while interacting with the machines. This involves visiting home haemodialysis patients or carers and interviewing them on their experiences. Additionally, if a patient or carer is interested in helping capture data about incidents involving the machines, we are lending them pocket-size high-definition Flip camcorders to maintain video diaries. My research is part of a large UK Research Council funded project, CHI+MED, that aims to improve the usability and safety of medical devices (www.chi-med.ac.uk).

I am currently looking for home haemodialysis patients or carers who would be interested in participating in the study, preferably in the Greater London area, but I would be willing to travel to other areas as well. I have obtained approval from the NHS Research Ethics Committee for doing this study. The REC reference number is 11/LO/0329. Please note that all data will be anonymised and treated confidentially.

If you would like to participate, please get in touch with me. My email address is atish.rajkomar.09@ucl.ac.uk and my telephone number is 020 7679 0363.

Atish Rajkomar

The National Kidney Federation cannot accept responsibility for the views expressed by others in these letters pages.

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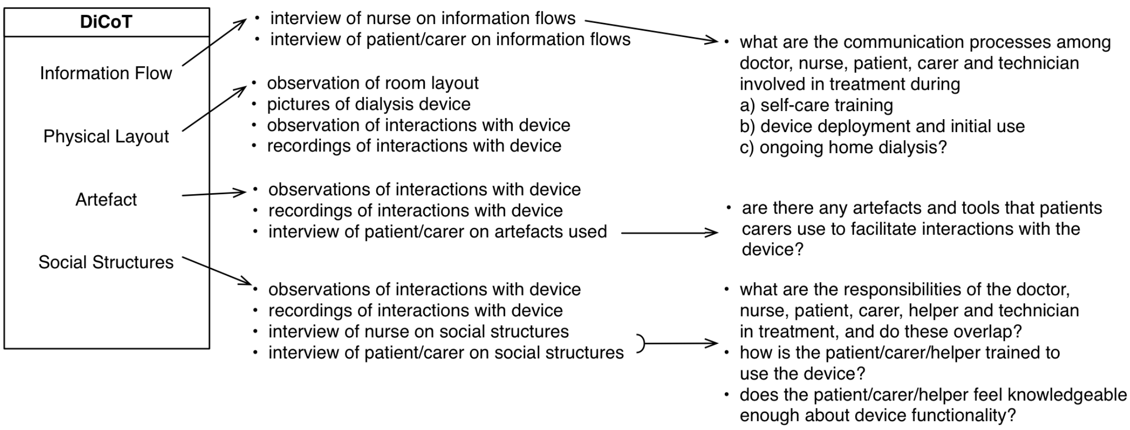
Page created: 9 September 2011
Last updated: 9 September 2011

B.4 Using DiCoT to structure data gathering



Appendix C: Methods of Preliminary Study

C.1 Home Visit Guide

(N) is intended number of minutes on that topic

Home Visit Guide

Observation

- Observe start or end of dialysis session

Study information and consent (5)

- Study to understand how people use medical devices in the home, to improve design of the device so they are safer and easier to use
- Anonymisation of data, confidentiality, discarding of audio/video data

Patient background (5)

	Patient	Carer	Helper
Name			
Relation			
Gender			
Age			
Family			
Job			

Dialysis (5)

1. When did patient start dialysis?
2. When did patient start home haemodialysis?
3. What is the current dialysis regime?
4. What are the typical dialysis parameters used?
5. Does the patient have other medical conditions that influence dialysis?

The technology in general (5)

6. What are the main steps in using this machine (NxStage)? Is it the same as other ones, i.e disinfection, connection and termination or very different?
7. How technology savvy is the user, experience in using similar technologies?
8. Eliciting user's general mental model of the technology, friend or monster?
9. How does a typical dialysis day look like?
10. What is the impact of the technology on daily life?
11. Does the patient/carer conduct other activities during dialysis?

Experiences of interacting with the device (15)

12. Critical incidents
13. Eliciting user's mental model of device for tasks they find difficult, or in general
14. Making sense of device's language and alarms
15. Strategies developed to facilitate interactions with the device, things done differently
16. Artefacts and tools that patients/carers use to facilitate interactions with the device
17. What do they like about the device?

Social structures (10)

18. How does the patient/carer view the responsibilities of other people involved in treatment, i.e doctor, nurse, carer, helper, and technician?
19. Do they feel independent in their treatment, and how does device contribute to that?
20. How does the patient/carer/helper feel about the training?
21. Does the patient/carer/helper feel confident in using the device?

Physical Layout (5)

- Ask permission to take pictures, or sketches, of room layout and device setup

Diary of incidents (5)

- Ask if willing to keep diary of incidents or near misses, through camcorder, or pen and paper
    - If camcorder option accepted, take out and show Flip
    - Patient/carer can record whatever they are comfortable recording, when it suits them
        - demonstrate power on
        - demonstrate start/stop recording
    - Can review videos and delete them if desired, submit only videos they are ok with
        - demonstrate video playback
        - demonstrate video deletion
    - Videos will be anonymised, analysed, transcribed, and then deleted
    - Tripod can be used to place camcorder on a surface and allow hands-free recording
        - take out and show tripod
        - demonstrate tripod connection
    - If patient dialyses, carer/helper or other family member can record
    - If carer/helper dialyses, other family member can record
    - If prefer not having any people in the footage, can record only device and display, with voice-over
    - Charge battery by USB connection to computer
        - demonstrate USB port switch
    - Download videos to computer through USB connection
    - Hand over Quick Start guide
    - What to do when memory is full? (8 GB, 2 hours footage)
        - Call me to come pick up the data
        - Or download videos to their computer, delete from the camcorder and continue recording
- Otherwise ask if they already have a diary of incidents, and if they do, ask permission to look at it and take pictures of it

Wrap-up (5)

- Arrange next meeting to pick up diary, if applicable, or ask if could be interviewed again in the future
- Thank for participation
- Possibility of sending report to them later

C.2 Examples of interview transcript (for Carl) and observation notes (for Cindy & Eric)

Interview transcript for Carl

Date: 2 Aug 2011
Time: 15:45
Location: Patient's living room
Participant: Carer

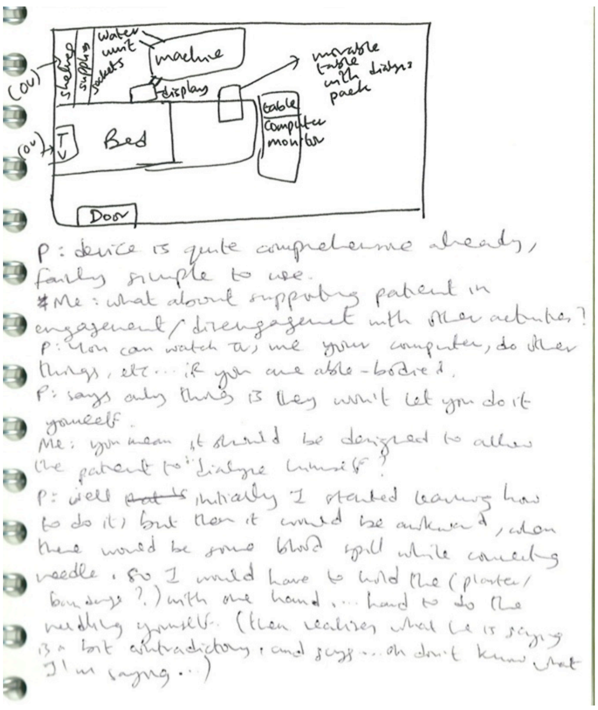
R: Researcher
C: Carer

R: So just to get a brief background, do you have a job?
C: No, I'm actually retired. I'm 53. Because of diabetes and other medical complications, I've been retired on medical ground.

R: so it's just your dad and your mum who live here?
C: yes
R: it's only you who does the dialysis?
C: yeah
R: you don't have any other helper who was trained, no?
C: uh, well you know, my dad's got a big network of support. I've got 2 other brothers and a sister, and I've got my sons as well. So, you know, for example if I can't make it, if I can't take him to meet hospital appointments, there's always many other options as well, but I'm the only one who's been trained to dialyse him. But I suppose, my brothers have asked, well basically they said, if you train us, ok, we're quite willing to do it as well. Maybe that's an option. I don't know how Diane would view this, whether they would need to be trained…at the unit, rather than me, tr – I don't know, how, you know, what's the procedure on that. But you know, a big network of support, yeah.

R: typically what parameters you would use on the machine?
C: the parameters? Oh…well obviously I need to put certain data on, for example how many hours is he going to be dialysed, how much fluids we're gonna take from him. Obviously, you know, someone who's kidney is not functioning, *they tend to be* a lot of fluids, you know, my father doesn't pass much urine, so the body eh the fluid stays in the body. That's one of the objectives of the machine, is to take fluids out. So depending on um ah his weight, you know, depending on his dry weight, that will determine how much fluids. So that's the data we need to put on: the hours, how much fluids and for example, you know, like for example the umm the solution that they use, the sodium, there's different types of sodium. So I actually need to put the

Handwritten observation notes for Cindy & Eric



Typed up notes for Cindy & Eric

P: device is quite comprehensive already, fairly simple to use

R: what about supporting the patient in engagement/disengagement with other activities?

P: you can watch TV, use your computer, do other things, etc.. if you are able-bodied

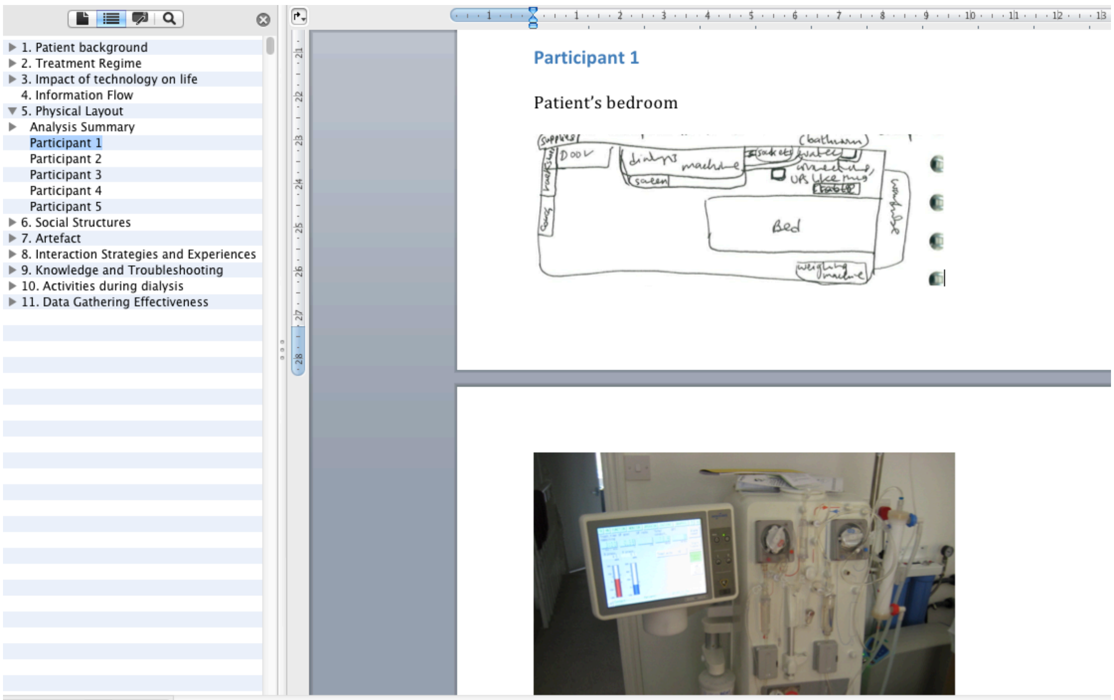
P: only thing is they won't let you do it yourself

R: you mean it should be designed to allow the patient to dialyse himself?

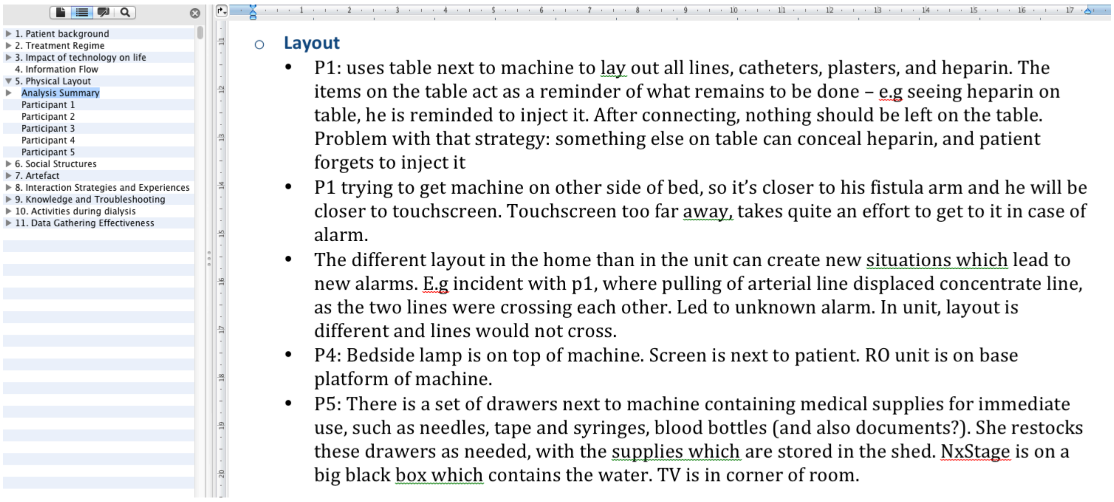
R: well initially I started learning how to do it, but then it would be awkward, when there would be some blood spill while connecting the needle. So I would have to hold the *plaster/bandage?* with one hand…hard to do the needling yourself…

C.3 Sample of top-down DiCoT analysis in "Physical Layout" section of analysis document

C.3.1 Sample of analysis of layout for Adam



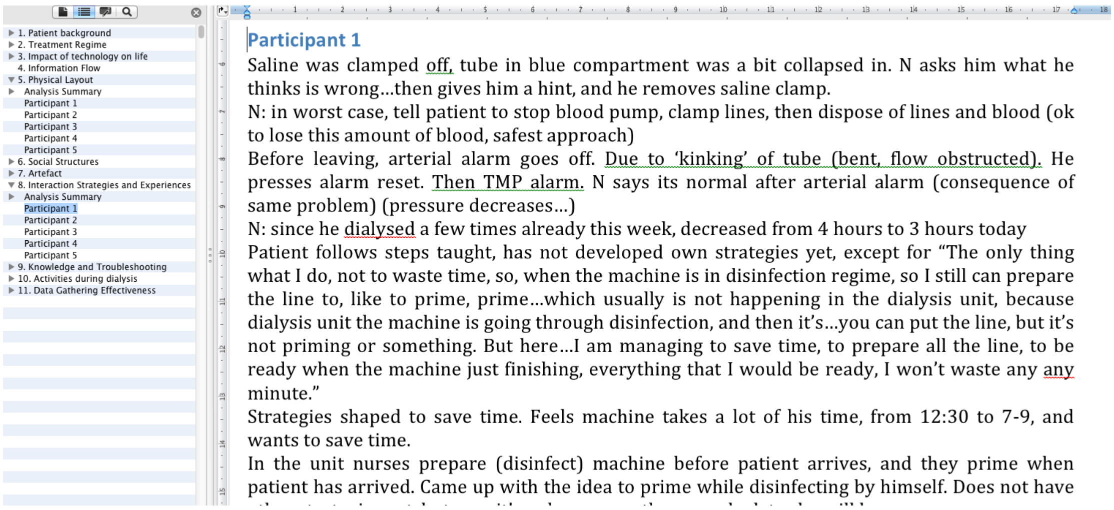
C.3.2 Sample of summative analysis of layout for all five participants


1. Patient background
2. Treatment Regime
3. Impact of technology on life
4. Information Flow
5. Physical Layout
Analysis Summary
Participant 1
Participant 2
Participant 3
Participant 4
Participant 5
6. Social Structures
7. Artefact
8. Interaction Strategies and Experiences
9. Knowledge and Troubleshooting
10. Activities during dialysis
11. Data Gathering Effectiveness

- Layout
  - P1: uses table next to machine to lay out all lines, catheters, plasters, and heparin. The items on the table act as a reminder of what remains to be done – e.g seeing heparin on table, he is reminded to inject it. After connecting, nothing should be left on the table. Problem with that strategy: something else on table can conceal heparin, and patient forgets to inject it
  - P1 trying to get machine on other side of bed, so it's closer to his fistula arm and he will be closer to touchscreen. Touchscreen too far away, takes quite an effort to get to it in case of alarm.
  - The different layout in the home than in the unit can create new situations which lead to new alarms. E.g incident with p1, where pulling of arterial line displaced concentrate line, as the two lines were crossing each other. Led to unknown alarm. In unit, layout is different and lines would not cross.
  - P4: Bedside lamp is on top of machine. Screen is next to patient. RO unit is on base platform of machine.
  - P5: There is a set of drawers next to machine containing medical supplies for immediate use, such as needles, tape and syringes, blood bottles (and also documents?). She restocks these drawers as needed, with the supplies which are stored in the shed. NxStage is on a big black box which contains the water. TV is in corner of room.

C.4 Samples of bottom-up analysis in "Interaction Strategies and Experiences" section of analysis document

C.4.1 Sample of analysis of one participant's data (Adam)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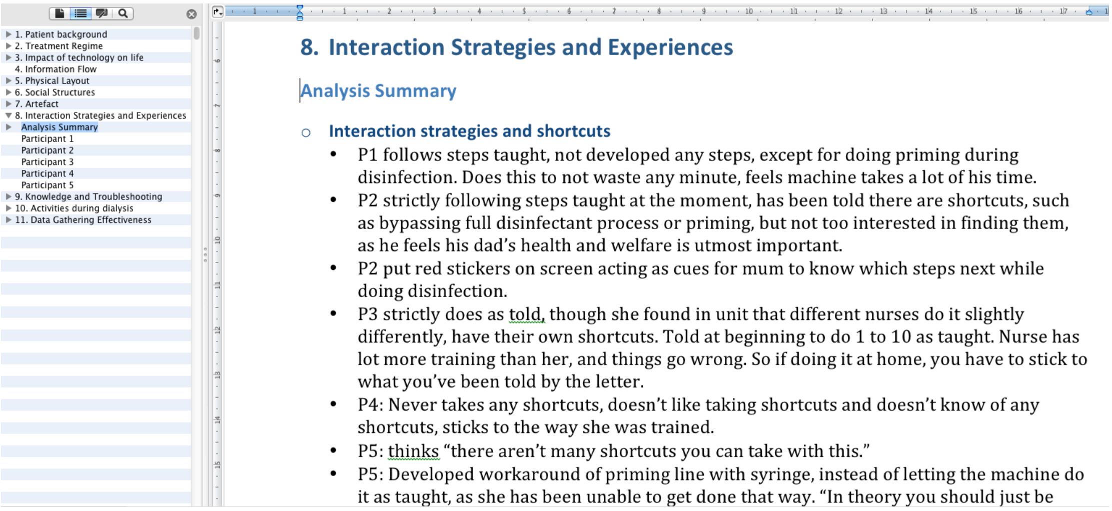
11. Data Gathering Effectiveness

Participant 1

Saline was clamped off, tube in blue compartment was a bit collapsed in. N asks him what he thinks is wrong…then gives him a hint, and he removes saline clamp.
N: in worst case, tell patient to stop blood pump, clamp lines, then dispose of lines and blood (ok to lose this amount of blood, safest approach)
Before leaving, arterial alarm goes off. Due to 'kinking' of tube (bent, flow obstructed). He presses alarm reset. Then TMP alarm. N says its normal after arterial alarm (consequence of same problem) (pressure decreases…)
N: since he dialysed a few times already this week, decreased from 4 hours to 3 hours today
Patient follows steps taught, has not developed own strategies yet, except for "The only thing what I do, not to waste time, so, when the machine is in disinfection regime, so I still can prepare the line to, like to prime, prime…which usually is not happening in the dialysis unit, because dialysis unit the machine is going through disinfection, and then it's…you can put the line, but it's not priming or something. But here…I am managing to save time, to prepare all the line, to be ready when the machine just finishing, everything that I would be ready, I won't waste any any minute."
Strategies shaped to save time. Feels machine takes a lot of his time, from 12:30 to 7-9, and wants to save time.
In the unit nurses prepare (disinfect) machine before patient arrives, and they prime when patient has arrived. Came up with the idea to prime while disinfecting by himself. Does not have

C.4.2 Sample of summative analysis for one theme (interaction strategies and shortcuts) for all five participants



8. Interaction Strategies and Experiences

Analysis Summary

- **Interaction strategies and shortcuts**
  - P1 follows steps taught, not developed any steps, except for doing priming during disinfection. Does this to not waste any minute, feels machine takes a lot of his time.
  - P2 strictly following steps taught at the moment, has been told there are shortcuts, such as bypassing full disinfectant process or priming, but not too interested in finding them, as he feels his dad's health and welfare is utmost important.
  - P2 put red stickers on screen acting as cues for mum to know which steps next while doing disinfection.
  - P3 strictly does as told, though she found in unit that different nurses do it slightly differently, have their own shortcuts. Told at beginning to do 1 to 10 as taught. Nurse has lot more training than her, and things go wrong. So if doing it at home, you have to stick to what you've been told by the letter.
  - P4: Never takes any shortcuts, doesn't like taking shortcuts and doesn't know of any shortcuts, sticks to the way she was trained.
  - P5: thinks "there aren't many shortcuts you can take with this."
  - P5: Developed workaround of priming line with syringe, instead of letting the machine do it as taught, as she has been unable to get done that way. "In theory you should just be

Appendix D: Methods of DCog Analysis

D.1 Home Visit Guide for first visit

Home Visit Guide

Observation

- Observe start or end of dialysis session

Study information and consent

- Study to understand how people use medical devices in the home, to improve design of the devices so they are safer and easier to use
- Anonymisation of data, confidentiality, discarding of audio/video data

Participant background

	Patient	Carer	Helper
Name			
Relation			
Gender			
Age			
Family			
Job			

Dialysis

1. When did you start dialysis?
2. When did you start home haemodialysis?
3. What is your current dialysis regime?
4. Do you have other medical conditions that influence dialysis?

The treatment

5. In general, what are the things you have to do as part of your treatment?
6. How does a typical dialysis day look like, what do you do on that day?
7. At what time do you usually dialyse, and why?
8. Talk me through the steps you take to prepare yourself, before starting connection
9. What are the steps you take to get connected to the machine and undergo dialysis?
10. What are the typical dialysis parameters that you use?
11. What do you do while you are on dialysis?

The technology in general

12. Do you view the machine as a friend or as a monster?
13. What is the impact of the machine on your daily life?
14. Tell me about your experiences of having the machine in the home

Experiences of interacting with the machine

15. Is there anything that you find tricky or difficult to do with the machine?
16. Can you understand the machine's messages and the alarms?
17. Have you found any shortcuts or ways to facilitate your use of the machine?

18. Is there anything you do differently than taught at the unit?
19. Have you had any incidents with the machine?
20. What do you like about the design of the machine?
21. What do you dislike about the design of the machine?

Social structures

22. Do you feel confident in using the machine?
23. How long did you get trained for, and how do you feel about the training?
24. Is there any family member or friend who helps you with any aspect of your treatment?
25. Does anyone else from your family, relatives or friends interact with the machine?
26. Tell me about your experiences of interacting with the other people involved in your treatment, i.e consultant, home nurse, unit nurse, carer, helper, and technician?
27. How do you ensure that your treatment is safe and that you can get help if needed?

Information flow

28. Tell me about your experiences of keeping a dialysis chart

Physical layout

29. Ask permission to take pictures, or sketches, of room layout and machine setup
30. Why do you dialyse in this particular place, and why is it set up the current way?
31. Where do you keep the dialysis supplies, why, and how do you manage them?
32. Where do you keep the following, and why:
    a. blood pressure monitor
    b. weighing machine
    c. dialysis chart
    d. medications
    e. telephone

Diary of incidents

- Ask if they already have a diary of incidents, and ask permission to take pictures of it
- Otherwise ask if willing to keep diary, through camcorder, or pen and paper

Wrap-up

- Arrange next meeting to pick up diary or ask if could be interviewed again in the future
- Thank for participation

D.2 Home Visit Guide for second visit (individual to each participant)

Acronyms used in the home visit guide

Art: Artefact model

Art Rep Res: Artefact model, Representation of Resource principle

Art Rep-Goal: Artefact model, Representation-Goal Parity principle

SS Goal: Social Structures model, shared Goal principle

Temp Routines: Temporal model, Routines principle

PL Arrange: Physical Layout model, Arrangement of Equipment principle

IV: Interviewer

Home Visit 2 Guide – P6

Observation

- Observe start or end of dialysis session

Updates

1. Any new incidents since last visit?
2. Any new shortcuts or things done differently from training to facilitate interactions?

General clarifications

3. Walk me through your steps in preparing for dialysis and connecting to the machine and starting dialysis
4. At what time do you usually dialyse, and why?
5. What are your experiences of keeping a dialysis chart?
6. Where do you keep the following, and why:
   a. blood pressure monitor
   b. weighing machine
   c. dialysis chart
   d. medications
7. ever needed to change sodium bicarbonate?
8. Yes, I suppose I do, really. As far as aligning the machine is concerned, everything that isn't connected to anything, all these that are not connected I just clip them off, and what I do, I systematically go round them all now to make sure that they're all shut.

DC clarifications

9. Art Incident: how did wife turn on saline during incident?
   James found it ok to dispense saline, with instructions from the home nurse on the phone.
   "No, there's a clip that goes to another bottle and you open that clip and the roller and that goes into another one that just gives you saline back. That's all."
   "Oh fine. Yes, I didn't have any problem. Once she explained to me what to do it was quite easy. Yes."
10. Art Design: example of odd message he doesn't understand?
   I... it does alarm at different times that I don't know why. I had one on Monday, did I? It kept alarming and I didn't know why. And in the end I undone one of the screws and released it, and it must have released something because I put it back in and it was fine. I don't know why. 00:08:06 IV Which screw? James: It's one that goes into the machine. It screws into the machine. I think what they are, they're like airlocks, you know. And this one must have got something in it because when I released it it was all right. You... but you remember what the message was in that case? Were you...? You said... 00:09:06 James: Yes, just low pressure alarm. IV Not in the water pressure one but when you had to screw the connection. James: Yes, just high pressure. That's all. IV Just high pressure? James: Yes.

11. Art Rep Res: leaving some (clamps?) open as safety ones, to tell you when there's blood in them
    Not able to clarify this, doesn't make sense to him anymore
12. Art Rep-Goal: check if water pressure gauge has target dial
    Didn't check this
13. SS Goal: in the passing out incident, was it saline or water that wife turned on?
    saline
14. Temp Routines: Why does he clean after dialyzing – ready to go the next day – motivation?
    Just wipes machine's front with cloth and cleaning liquid, in case there is any spillage, but there never is
15. PL arrange: why is everything in a closed circle? (supplies, bins, bp, weighing)
    IV And I saw that... when we went in your room last time I saw you've got the blood pressure monitor by the bed, the weighing machine and everything. So you keep everything there? James: Yes, everything's upstairs so that we don't have it spread all over the house. 00:03:51 IV And does it, kind of, facilitate your...? James: Yes. What I do, I go in and shut the door and I don't come 3 out for three hours. IV So you do everything there
16. PL arrange: is there a specific reasoning behind placement of tray for coming off?
    IV Last time I saw you, you have your tray... the tray that use when you're coming off is always on your bed to your right there so it's, kind of, ready for you to use as soon as you come off. James: Yes.

CF clarifications

Participant's phenomena

17. 58: how is it untidy to have machine in the home?
    IV So the last time you were mentioning that Karen thinks it's, kind of, untidy to have it in the home. James: Yes, well... IV Why does she think so? James: You still think it's untidy, don't you? 7 00:13:11 Karen: I'm a bit of a control freak unfortunately. Everything in its place has got a place. But it doesn't bother me. IV It doesn't bother you. Karen: You know, it's all there. It's got to be done. And it doesn't worry me to that extent. If it starts coming in here as well then it's a problem, but no, I'm not that worried. I've got more things to worry about at the moment. 00:13:35 IV But you... it would be a problem in terms of making a mess in the room or just because...? Karen: Yes, it's just being generally untidy. I mean, I sometimes go in and tidy up. James's not the tidiest of people. But I'm inclined to go round and straighten papers and straighten towels on racks, but that's just me. Not a problem. It's only my problem
18. 60: still not dialyzing on weekend due to support unavailable?
    And, James, you mentioned that you were not dialysing on weekends because there was no support available. So do you... you're still not dialysing on the weekend or...? 00:14:13 James: I haven't up 'til now, but I've decided that I probably will do a Saturday morning. What I... I'd... what I'd been doing, because Karen has been going to chemotherapy on Thursdays, I've been doing Monday, Tuesday and Wednesday and Friday. 00:14:37 But I think now what I'll do, I've found that having three days on the run made me feel rough, so I think it's too much. So I think I might do Monday, Wednesday, Friday and Saturday. That might be... next week that might be the better idea. I'll see how I feel next week anyway. I tried to leave the weekend free. 00:15:08 Karen: While he was learning we didn't want to not be in touch with the Royal Free, but now he seems as though he's.... James: Yes, I've got it all off. Karen: ... got control of it all we're not quite so concerned about being in touch. So you said you'd like to give it a try, didn't you, for Saturday next

week? 00:15:23 James: Yes. In fact the home nurse did suggest that I done one day over the weekend. Karen: It'll probably be better for you.

19. 67: where does he keep the instructions?
    And you still keep it around in case you need to... in the room? 00:16:33 James: Yes.
20. 69: if he doesn't read, what does he do while on dialysis, just relax?
    So what do you do then while you're on dialysis, while you're dialysing? James: I don't do a lot. I read the paper. 00:17:26 Karen: And you sleep. IV You don't watch TV or anything; you rest and sleep? James: Yes. Karen: He sleeps very easily, my husband. James: Yes. I was... we were going to get a television, but I was waiting 'til we turn over to digital really. Karen: Yes, we've got to go out and find one, but we... because the one upstairs we've got is no good, is it? James: They're going to digital on April 12 th , so... although it's... Karen: We've got an old one up there, but it's broken, so we've got to get that down and get a new one. But that would be an advantage for him. 00:18:00 James: Yes. I can do longer then. IV So then you're planning to have a TV? James: Yes.
21. 71: why does he clean after dialyzing, to connect quickly next day?
    above
22. 72: why does he put plasters on edge of screen?
    IV I saw that you stick some of the plasters on the edge of the screen. Is that something you learn on the unit or you just came up with this idea by yourself? 9 00:18:28 Karen: Just somewhere to put them I think. James: Yes, it's just somewhere to put them. Karen: They used to put them on the table in front of them, and having no table there...
    Yes. When you're in a unit you have a table in front of you, and the nurses, when they do the needles they usually stick them on the table, but I stick them on the screen. It's just it's simple for me to turn round and get the plaster and just put it on my arms, you see.
23. 75: why are supplies everywhere in the bedroom?
    above

Other phenomena

24. G2: do you sometimes adapt your dialysis time to be able to do other activities?
    I wanted to ask you if you sometimes adapt your dialysis time to be able to do other activities in the home, but I guess you... 00:19:46 James: Oh yes, we would do, yes. IV ... obviously have to because of hospital appointments and... yes. James: I have to, yes.
25. G3: do you have some ways of optimising on the time you spend with the whole dialysis process?
    What I usually do first thing in the morning, I usually line it out while Karen's having a shower and then I go in the shower when she comes out. And when I come out I have my breakfast and the machine's all ready for me to start.
26. G9: is there anything you feel uncomfortable doing with the machine, and avoid doing?
    I mean, the whole thing's uncomfortable, but no, I can't think of anything

Extraordinary use

27. Tell me about your understanding of how the machine works, in terms of what the different components do during your treatment
28. Tell me about your steps and thought process in dealing with common alarms:
    a. a/v pressure
    b. air bubble
    c. water pressure
    d. concentrate
29. How would you respond to a new alarm or problem situation?
30. Has it ever happened that something was wrong but the machine didn't alarm?

Diary

31. Ask if any new entries to personal troubleshooting diary, or discuss research diary

Physical Layout

- Observe any changes or new interesting things about the physical layout

D.3 Examples of interview transcript (Jill) and observation notes (Ivan)

	IV	Have they ever had to intervene, to go and make a phone call for you, say?
00:37:57	IE	They haven't had to make a phone call, but I remember once when I was having problems I did feel I was sort of passing out. You know, I could feel myself going and I called out to my mum, or something, I think. And she heard me, so she came up, and then, you know, I sort of, said, you know, get my head down and get my feet up, lift my feet.
00:38:21	IE	And so they did that, and then I sort of regained consciousness, but I think that's happened once, or twice maximum. You know, I was obviously having just a problem then, but that's not a regular occurrence, no.
	IV	Okay. I have just four more questions.
	IE	Okay, that's fine. No problem.
	IV	So I'd like to understand a bit more about the physical layout of where you do the dialysis, in terms of how you keep all the things that you need for your treatment, and if there is a reason why you keep some things there?
00:39:00	IE	Yes.
	IV	And how it actually fits your, how the arrangement actually fits in your life [?], in a sense?
	IE	Okay.
	IV	So first of all, why do you dialyse, why did you choose to dialyse where you dialyse? Is it in your bedroom, for instance?
00:39:13	IE	No, no, it's just a small, like a box room, and we've only got a small house anyway so it was the only spare room that we had, so it had to be there, yes.
	IV	So the reason you dialyse there is because there is a restriction of space as to where you could [overtalking]?
	IE	Yes, that's the only room that we have, yes.
	IV	Will it be possible for me to take a look at it?
00:39:39	IE	Yes, no problem. Yes, that's fine. It might be a bit messy, because Anthony is up there, but it's no problem.
	IV	Where do you keep your dialysis supplies?
00:39:47	IE	Yes, exactly, that's the big thing, because the room is tiny, but sort of, when I first started dialysis we had… Our kitchen used to be small, so we had the kitchen extended, and I would just keep the stock in the kitchen, on the shelf. So that was for several years we had that, but then it's not nice. It's messy. The stock is massive.
00:40:06	IE	So then we decided to build a brick shed at the bottom of our garden, and so now all the stock is kept at the bottom, and when the delivery comes the driver puts it there at the bottom of the garden, in the shed. And so, sort of, twice a week Dad and I will go and bring in enough stock for the next three or four days, so we sort of do it like that.
	IV	And that stock for the next two or three days, do you put it in the room?
00:40:33	IE	In the dialysis room, yes. There's enough space in there for stock for, well, one week, you know, but there isn't any room for anything else.
	IV	And this consists of the bicart, or what other things?
	IE	So it would be, you'd have the dialyser itself, and then you'd have the lines that you line the machine with. Then you would have the concentrate, which is the bottles of the fluid.
00:40:56	IE	Then you would have the bicart, which is the thing that I was having problems with, that plastic bottle, and then you would have, like sterile dressings packs, and things, you know, for when you're doing the work, and renal packs. And you'd have syringes, and needles, and hand rubs, you know, to clean your hands, and

12

He clicks on ~~one of the~~ [on top of chart] touchscreen buttons and gets the msg:
17:15 → Dialyser coupling is detached. Ah! Why didn't you say that before! And he tries to fix dialyser coupling. Seems to be alright (re-loading again…) Problem still not fixed…
→ setting treatment – wants to put 2:00, but it ends up as 0:00. He proceeds and then realises it's not been set – so he sets it again, this time succeeds.
→ puts plasters on lower edge of screen, with a pad attached

Typed up notes

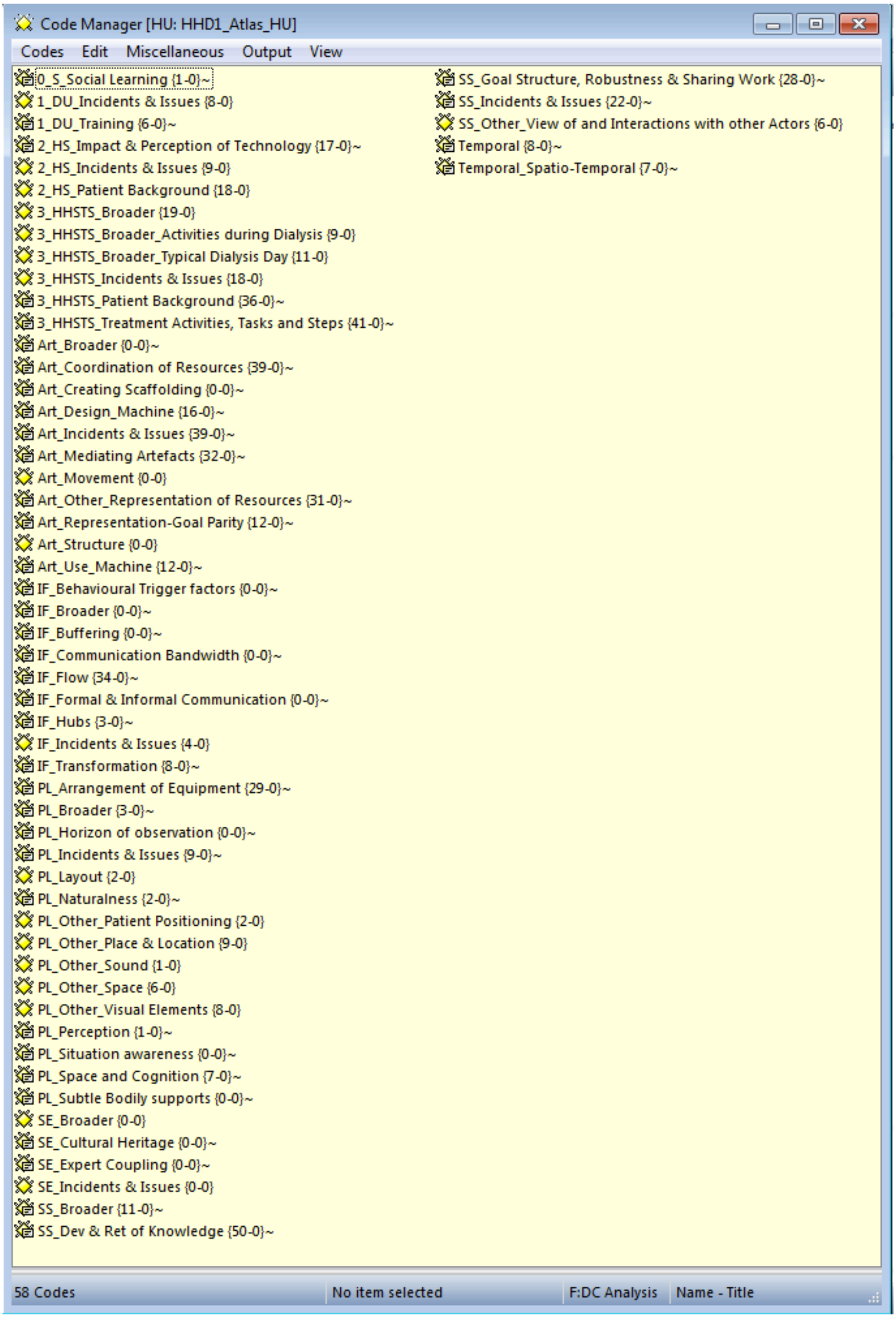
He clicks on one of the touchscreen buttons and gets the msg:

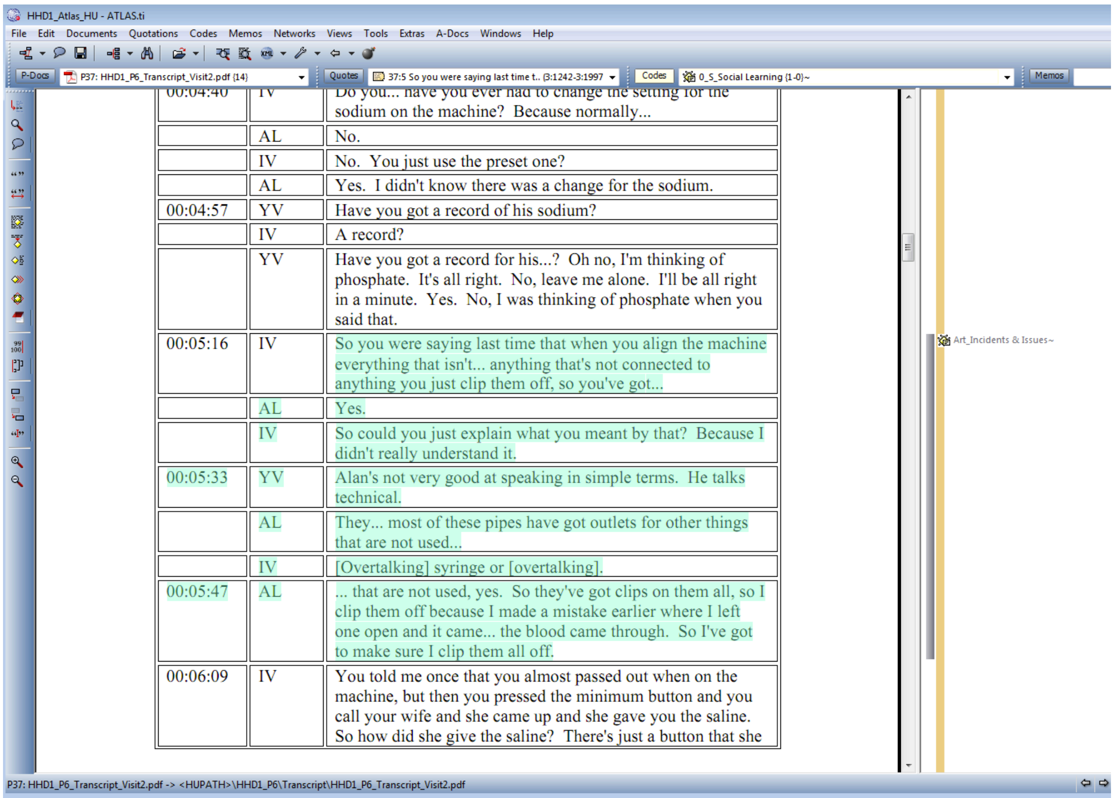
17:15 -> Dialyser coupling is detached. Ah! Why didn't you say that before! And he tries to fix dialyser coupling. Seems to be alright (recording again…) Problem still not fixed…

-> setting treatment: wants to put 2.00 but it ends up as 0.00. He proceeds and then realizes it's not been set. So he sets it again, this time succeeds.

-> puts plasters on lower edge of screen, with a pad attached

D.4 List of ATLAS.ti codes and example of coded interview transcript (Ivan)





00:04:40	IV	Do you... have you ever had to change the setting for the sodium on the machine? Because normally...
	AL	No.
	IV	No. You just use the preset one?
	AL	Yes. I didn't know there was a change for the sodium.
00:04:57	YV	Have you got a record of his sodium?
	IV	A record?
	YV	Have you got a record for his...? Oh no, I'm thinking of phosphate. It's all right. No, leave me alone. I'll be all right in a minute. Yes. No, I was thinking of phosphate when you said that.
00:05:16	IV	So you were saying last time that when you align the machine everything that isn't... anything that's not connected to anything you just clip them off, so you've got...
	AL	Yes.
	IV	So could you just explain what you meant by that? Because I didn't really understand it.
00:05:33	YV	Alan's not very good at speaking in simple terms. He talks technical.
	AL	They... most of these pipes have got outlets for other things that are not used...
	IV	[Overtalking] syringe or [overtalking].
00:05:47	AL	... that are not used, yes. So they've got clips on them all, so I clip them off because I made a mistake earlier where I left one open and it came... the blood came through. So I've got to make sure I clip them all off.
00:06:09	IV	You told me once that you almost passed out when on the machine, but then you pressed the minimum button and you call your wife and she came up and she gave you the saline. So how did she give the saline? There's just a button that she

D.5 Example of quotations document (Jill) with quotations grouped by DiCoT principle

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Code: PL_Space and Cognition {4-0}~

P25: HHD1_P7_Transcript.pdf - 25:47 [And when you keep them in the ..] (13:103-13:497) (Super)
Codes: [PL_Space and Cognition - Family: DC Analysis]
No memos

And when you keep them in the dialysis room, do you keep them in a particular way, or they are just there and then you just pick something?
IE No, no, I have little baskets for everything, so the dialysers go in one basket and the renal packs go in another basket. So, well, you can see when we go up, but on the wall there's just baskets and they, sort of, fit together in a basket.

P25: HHD1_P7_Transcript.pdf - 25:48 [Yes, so when I'm preparing for..] (13:651-13:1033) (Super)
Codes: [PL_Space and Cognition - Family: DC Analysis] [Practices_Coping - Family: CF Analysis]
No memos

Yes, so when I'm preparing for a session, you know, when I put the machine on and it's doing the heat disinfect, then I will just get the concentrate out that I need and put it by the machine, and the bicart that I would need and put it by the machine. And when I'm lining the machine then, you know, it's such a small room that you just go like this and you get everything.

Code: PL_Subtle Bodily supports {0-0}~

Code: SE_Broader {0-0}

Code: SE_Cultural Heritage {0-0}~

Code: SE_Expert Coupling {0-0}~

Code: SE_Incidents & Issues {0-0}

Code: SS_Broader {9-0}~

D.6 Example of paraphrasing quotation in analysis document (Jill)

- 1. HH STS
- 2. Information Flow
- 3. Physical Layout
  - PL Layout
  - PL Other – Place & Location
  - PL Arrangement of Equipment
  - PL Space and Cognition
  - PL Naturalness
  - PL Other Physical Elements – \
  - PL Broader
- 4. Social Structures
- 5. Artefact
- 6. Temporal

heparin on table, he is reminded to inject it. After connecting, nothing should be left on the table. Problem with that strategy: something else on table can conceal heparin, and patient forgets to inject it

- H1p2
  - before he used to start getting ready 5 mins before coming off. Now he does it 20 mins before, and takes out everything that is needed (syringes, wipes) and puts it onto table close to machine, and he knows where everything is. He does it very early to make sure he doesn't miss anything.
    - why did he change from 5 mins before to 20 mins before, for preparing things for coming off?
      Yes, as dad wants to come off as soon as possible. So he prepares everything so there is no delay.
  - Trolley has 3 shelves. Each shelf has a compartmentalized tray, each compartment containing a type of supply, e.g one for syringes, one for dressings
  - In supply wardrobe as well, supplies grouped together by type. IE Yes, I know where things are. You know, like, you know, the sodium is on the right-hand side; then I've got the dialyser at a certain place; I've got the fistula packs in certain places. I know where the syringes are, you know... 00:23:41 IV And you always keep them in a separate...? IE Yes, I know where it is.
  - Antibacterial wipe thing thing kept on top of machine as reminder to clean it after/before?
- H1p5
  - Arrangement on tray – reasoning behind?
    - New sterile pack, that will be used first when coming off, is on top, whereas old sterile sheet, which will be used later while disposing of the needles, is below
- H1p6
  - tray with things for when he comes off is on right side of bed
  - two drawers in a set of drawers for keeping supplies, top one for plasters and wipes, second one for dialysers and syringes.
- H1p7
  - keeps supplies in little baskets, each basket for one thing, e.g one for renal packs, one for dialysers
  - while preparing for a session, while disinfection, she gets concentrate needed and puts it by machine, gets bicart and puts it by machine, and when lining the machine she just goes like this and gets everything.

D.7 Example of entry in analysis document from analysis of a picture (Adam)

- 1. HH STS
- 2. Information Flow
- 3. Physical Layout
  - PL Layout
  - PL Other – Place & Location
  - PL Arrangement of Equipment
  - PL Space and Cognition
  - PL Naturalness
  - PL Other Physical Elements – \
  - PL Broader
- 4. Social Structures
- 5. Artefact
- 6. Temporal

PL Arrangement of Equipment

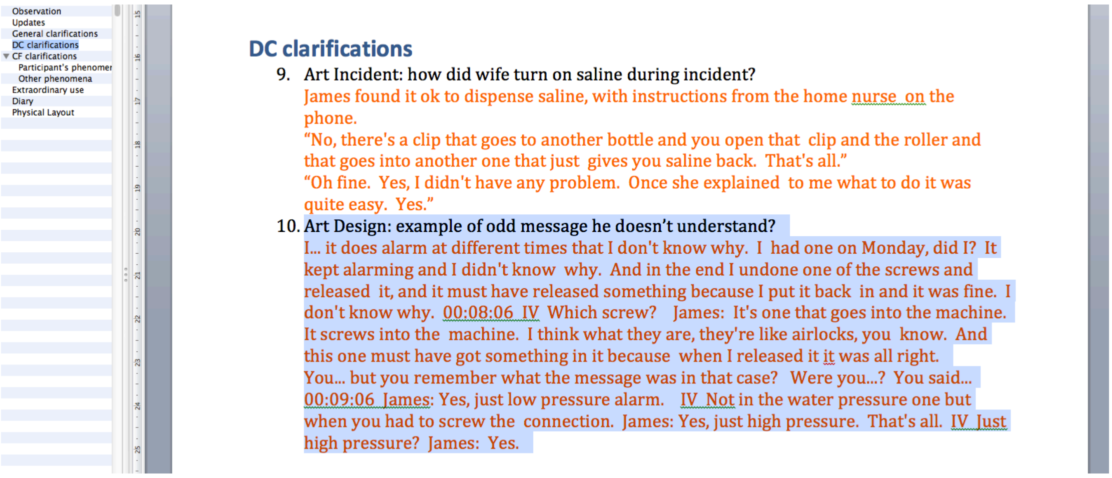
- H1p1
  - Keeps manual, dialysis diary and bp monitor on top of machine (see pictures)
  - Weighing machine next to bed
  - Supplies just outside room, by stairs
  - softener is in bathroom -> plumbing in wall -> filters, reverse osmosis unit -> final filter behind pump (to remove bacteria in between mixing)
- H1p2
  - trolley with supplies close to machine, weighing machine close to medical chair, wardrobe with supplies, table with dialysis docs, phone
  - bp monitor right next to medical chair on shelf, walkie talkies on shelf
  - calendar with injection dates on table next to dialysis site
  - patient positioned so that machine screen is very close to him, can see clock and also press minimum UF button if required
- H1p3
  - Gets everything ready that she will need before and after dialysis, so doesn't have to go searching around for stuff, and keeps extra supplies nearby in case something goes wrong. E.g needle broke once, and having spare one at hand makes it a little easier.
  - Shelves with supplies next to bed, and supplies on movable table next to bed
- H1p4
  - Bedside lamp is on top of machine. Screen is next to patient. RO unit is on base platform of machine.
  - Lamp is there so she can have more light while preparing for dialysis
  - Waste bin next to machine
  - Cleaning liquid on top of machine
  - likes that you can move the screen with the shrivel, so you can see it easier instead of having to stretch up, unlike other gambro machines where the screen is on the machine.
  - HHD patient contact list framed in top part of machine
  - Stock (main and intermediate) is in small room right next to her bedroom, walks back and forth around the corner to get supplies
  - Keeps bp monitor and weighing machine in room because everything else is there. May need bp monitor during dialysis if she's feeling light headed or going low.
  - Keeps dialysis chart in room in cupboard and takes it out when starting dialysis

D.8 Example of point for clarification during second visit (Ivan) in home visit guide and example of entry of clarification into analysis document

Acronyms in the home visit guide

Art: Artefact model

IV: Interviewer



Observation
Updates
General clarifications
DC clarifications
CF clarifications
Participant's phenomer
Other phenomena
Extraordinary use
Diary
Physical Layout

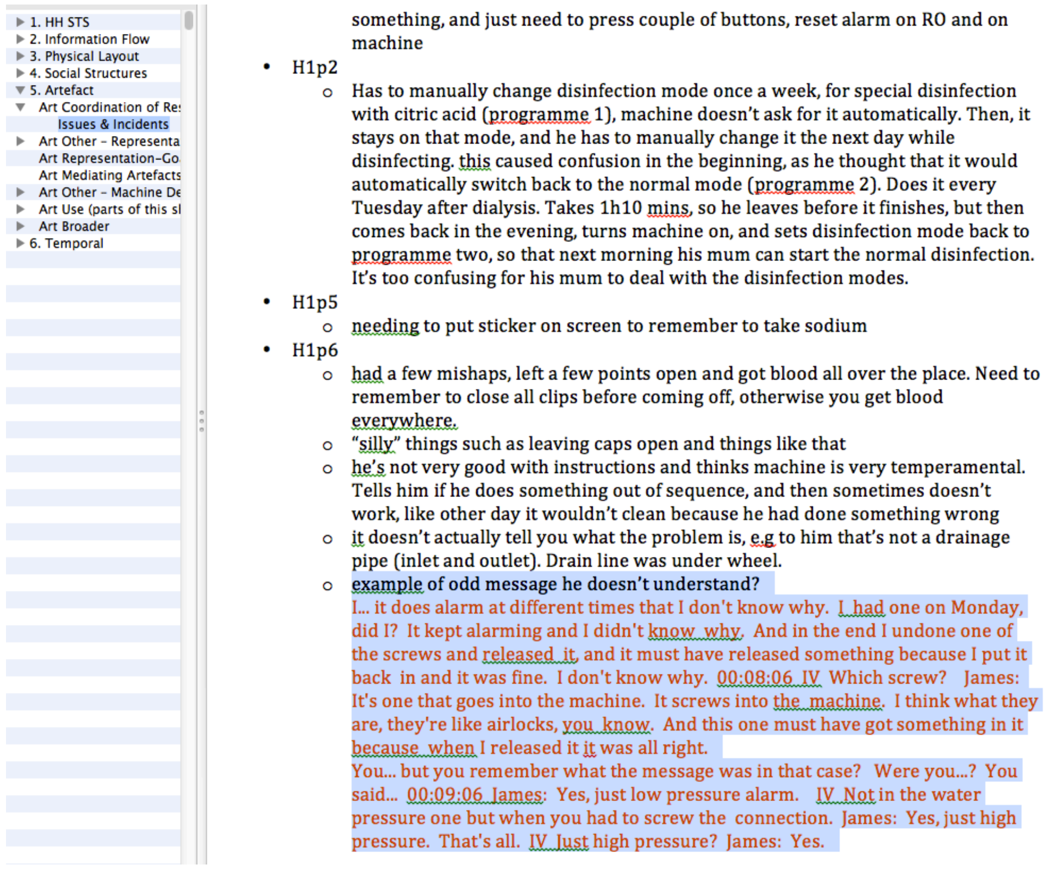
DC clarifications

9. Art Incident: how did wife turn on saline during incident?
James found it ok to dispense saline, with instructions from the home nurse on the phone.
"No, there's a clip that goes to another bottle and you open that clip and the roller and that goes into another one that just gives you saline back. That's all."
"Oh fine. Yes, I didn't have any problem. Once she explained to me what to do it was quite easy. Yes."
10. Art Design: example of odd message he doesn't understand?
I... it does alarm at different times that I don't know why. I had one on Monday, did I? It kept alarming and I didn't know why. And in the end I undone one of the screws and released it, and it must have released something because I put it back in and it was fine. I don't know why. 00:08:06 IV Which screw? James: It's one that goes into the machine. It screws into the machine. I think what they are, they're like airlocks, you know. And this one must have got something in it because when I released it it was all right. You... but you remember what the message was in that case? Were you...? You said... 00:09:06 James: Yes, just low pressure alarm. IV Not in the water pressure one but when you had to screw the connection. James: Yes, just high pressure. That's all. IV Just high pressure? James: Yes.

Acronyms in the analysis document

Art: Artefact model

IV: Interviewer

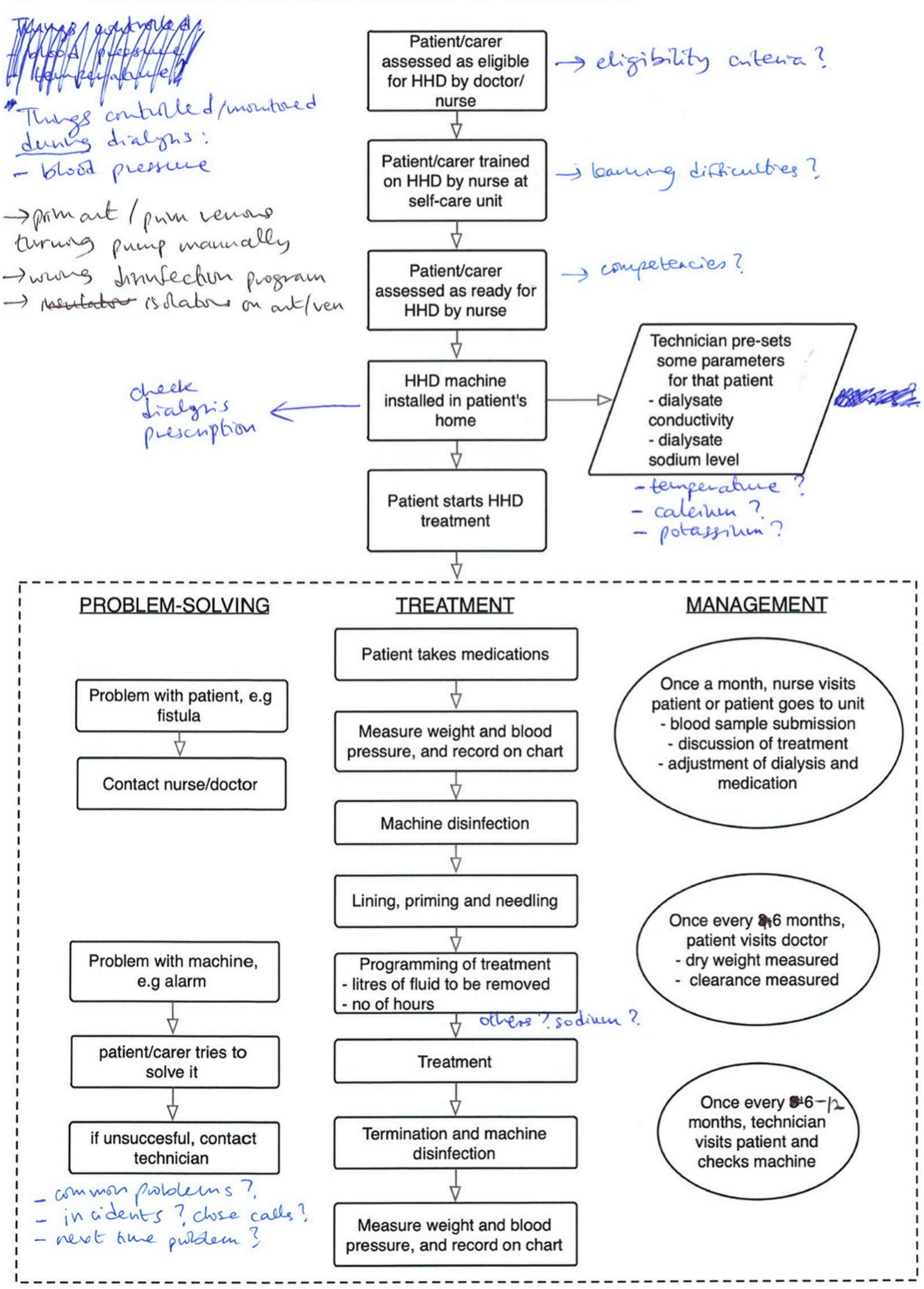


- 1. HH STS
- 2. Information Flow
- 3. Physical Layout
- 4. Social Structures
- 5. Artefact
  - Art Coordination of Re:
    - Issues & Incidents
  - Art Other – Representa
  - Art Representation–Go
  - Art Mediating Artefacts
  - Art Other – Machine De
  - Art Use (parts of this sl
  - Art Broader
- 6. Temporal

something, and just need to press couple of buttons, reset alarm on RO and on machine

- H1p2
  - Has to manually change disinfection mode once a week, for special disinfection with citric acid (programme 1), machine doesn't ask for it automatically. Then, it stays on that mode, and he has to manually change it the next day while disinfecting. this caused confusion in the beginning, as he thought that it would automatically switch back to the normal mode (programme 2). Does it every Tuesday after dialysis. Takes 1h10 mins, so he leaves before it finishes, but then comes back in the evening, turns machine on, and sets disinfection mode back to programme two, so that next morning his mum can start the normal disinfection. It's too confusing for his mum to deal with the disinfection modes.
- H1p5
  - needing to put sticker on screen to remember to take sodium
- H1p6
  - had a few mishaps, left a few points open and got blood all over the place. Need to remember to close all clips before coming off, otherwise you get blood everywhere.
  - "silly" things such as leaving caps open and things like that
  - he's not very good with instructions and thinks machine is very temperamental. Tells him if he does something out of sequence, and then sometimes doesn't work, like other day it wouldn't clean because he had done something wrong
  - it doesn't actually tell you what the problem is, e.g to him that's not a drainage pipe (inlet and outlet). Drain line was under wheel.
  - example of odd message he doesn't understand?
    I... it does alarm at different times that I don't know why. I had one on Monday, did I? It kept alarming and I didn't know why. And in the end I undone one of the screws and released it, and it must have released something because I put it back in and it was fine. I don't know why. 00:08:06 IV Which screw? James: It's one that goes into the machine. It screws into the machine. I think what they are, they're like airlocks, you know. And this one must have got something in it because when I released it it was all right.
    You... but you remember what the message was in that case? Were you...? You said... 00:09:06 James: Yes, just low pressure alarm. IV Not in the water pressure one but when you had to screw the connection. James: Yes, just high pressure. That's all. IV Just high pressure? James: Yes.

D.9 Dialysis flowchart that was validated by home nurse of H1



Appendix E: Interaction Strategies and Issues

Terms used in tables

IMG_1386 – reference to a picture

58:40 – reference to an ATLAS.ti quotation

IV – interviewer, in transcript extract

IE – interviewee, in transcript extract

E.1 Systems constituting home haemodialysis

Table E.1: Interaction strategies and issues related to broader systems

	Strategy/Issue	Example(s)
1	Patient engaging in HS activities while on dialysis (which they may not be able to do when dialysing in the unit)	• Fiona: watches TV • Gina: watches TV • Jill: watches TV • Alice: watches TV • Ivan: planning to get a TV into his dialysis room • Felix: 47:9,47: Watches TV, reads paper in afternoon. • Garry: 48:18: may watch TV or read or do work stuff • Jim: 50:10: watches TV or sleeps, has headphones set up, and music player • Kevin: 54:16: sits and thinks, writes, watches TV, rests and sleeps. catnaps, not sleeps – because conscious of dialysis, and doesn't want to sleep in case something happens. • Alice: doesn't see it as intrusion, people used to come around and have cup of tea while dialyzing, accept it's part of what she does now (hosting guests, a HS activity) • Bea: 43:33 • Eva: watches TV or reads or friends come to keep her company during dialysis.
2	Side-effects of dialysis limiting HS activities patient can engage in during dialysis	• Jill: occasionally tries to read, before used to sort of do a bit of work, but she gets quite headachy • Erica: 45:6: can't read book because of line in arm, so watches TV
3	Patient becoming focus of HS during dialysis	• Carl: when patient is on machine, patient becomes the focus of the home, attention is towards him, and always wary that something might go wrong. Carer and mum do other things, like cooking or reading or resting, but check on him from time to time and somehow

		occupied with him for 4 hrs.
4	HS activities hampered by Dialysis activity	• Felix: 47:73: son cannot shower after coming back from work due to water pressure thing. Also does not use washing machine at same time, though it seems to not affect it (as it is downstairs, and not upstairs like shower), as a precaution (47:38) • Kevin: 54:16: cannot sleep properly while on dialysis due to machine noise, also mentioned elsewhere that even machine off, makes noise at night and he has to sleep with that (54:4,25,26,27) • Adam: machine noise disturbing sleeping child • Erica: 45:8: cannot host guests anymore, as one bedroom, one bedroom turned to treatment room, one bedroom turned to storage room (before had 3 bedrooms) • Garry: 48:50: before used to takes dog for walk and do other stuff, now very limited • Ted: 57:7: When there were leakage problems, in first year, due to faulty equipment in water unit (valve or something), patients stayed in during pre-disinf and post-disinf, in case there was a leak. Otherwise if they went shopping they would be constantly thinking is it leaking is it leaking?
5	HS activities creating disturbances to Dialysis activity	• Erica: 45:13: got low water pressure alarm a couple of times, e.g. when washing machine was on downstairs • Adam: Due to problem with water pressure, try to adapt water use in house to dialysis: no shower, no washing machine, open tap just a little, cannot help if kid goes to toilet • Ivan: Sometimes wife starts washing machine before he starts to dialyse, creates alarm. Ok to put it on after he has started dialyzing, but not before. Once he couldn't understand why it was alarming, until his wife told him she had put washing machine on. • Cindy: Got water pressure alarm while son was using pressure hose in garden
6	Support arrangements with DUS influencing Dialysis activity	• Gina dialyses on Sunday, even though unit support not available. Last year she had tinzaparin incident on a Sunday, called 999. thinks they make you sign that you won't dialyse on weekend just to cover their backs. (and mentions that people dialyse in the unit on sat) she decided to do it alternate days, good for her, 4x good for her, gives her more privilege to eat what she wants (so one of the days falls on weekend, her choice) • Jill: it's really frustrating when the machine isn't working, because they

		haven't got a very good setup for home patients when machine isn't working, everyone is full up in the unit and nobody wants to take you. in the past she had lots of problems with the machine and the machine's drainage. she was panicking every time she was dialysis, in case something wouldn't work, and the pressure of not easily dialyzing in unit made it worse. • Ivan: doesn't dialyse on the weekend at the moment, doctor advised, as nobody around to give information, until he has dialysed for a few weeks • Carl: when there was water leak problem, halfway through, (machine kept stopping, restarting after alarm silenced and stopping again) engineer recommended that patient doesn't go on the machine and that patient dialyses in unit. Problem to get slot in unit: hard to get morning slot - preferred time for patient, doesn't like doing it in evening, too stressful for him, and doesn't want to go there and return home and just go to bed, also possibility no slot then as well. Patient said he didn't want to go there. So carer decided to resume at home, took the chance and stuck a tape on the spray, and did 2 more hours. • Ida: dialysing earlier as home unit will be closed after: 49:20 • Ida: unit advises patients to not leave two days off (weekend): 49:59 • Garry: fixing machine himself with hair dryer, problem dialysing in unit, prefers to fix himself, hadn't dialysed for a while. 48:60,53 • in beginning, while Ivan was learning, they wanted to be in touch with H1 while dialysing, therefore didn't do weekend. Now that he seems to have got control of it all, they will start doing on the weekend. Wants to do 4 days, and 3 days in a row makes him feel rough, it's too much. thinks he will do mon,wed,fri and sat. should be better for him.
7	Issues in DUS that inspired patient to go on HH	• Unit staff taking off fluid when not required, making her feel sick: Ida: 49:57,56. Now in control, and doesn't take fluid off (default is to take fluid off everyone) • Unit staff taking off fluid from patient when not required in her case: Bea: 43:6 • seeing nurses make mistakes: Bea: See 43:34. She saw nurses make mistakes, inspired to do it on her own, at least if mistake, it's her own fault. • nurse bursting patient's fistula: Gina: started doing her dialysis herself because the nurses tend to burst the

		fistula and the way they handle the fistula can be painful, while locating the fistula, despite of her telling them where it is (knowing her body). She was already setting the machine herself, which she learnt by observing nurses, but then from then onwards she did everything herself.
8	Other issues in DUS observed by patient	• some nurses contaminating supplies: Gina: knows some patients who got infected with HH. In the unit some nurses do not use proper sterile techniques and contaminate supplies, but since she's a patient she can't say anything. • nurse response time: Abi: only passed out in unit, not at home, as there nurse takes a while to come when she shouts for help. Whereas at home her mum comes immediately. 58:12. • nurse's busy, do things quickly, error: Abi: problem in DUS: 59:21: once nurse didn't tighten connection, got air inside of her. Phobia of bubbles since then. Nurses are on their feet all their time, so might do it quickly. At home she can take her time and do it properly. Also more calm at home. • no personal contact anymore: Beth: 62:24: in unit, nurses having time to speak to people before. now, just plugged in. people not comforted, don't know they will get better.
9	Being able to work, a SS activity, due to the flexibility provided by the Dialysis activity happening at home	• Gina: could work full time due to flexible HH. Worked till 5, dialysed from 8 till 11 or 12. • Garry: works full-time • Kevin: works full-time • Eva: works full-time. 67:19.
10	SS activities hampered by Dialysis activity	• Garry: 48:10: effect of using tinzaparin, blood doesn't clot, not good for chef, cut himself a month ago and didn't stop bleeding for two days • Eva: 67:41: dialysis making her tired. Needs to rest during work a bit, to recharge. Body doesn't accompany you on travel even though mentally you want.
11	Going on holiday, a SS activity, and taking machine to be able to do Dialysis activity	• Alice: taking (portable) machine to other places and on holiday • Garry: (48:55,48:19, 48:20, 48:28) • Extreme example of patient taking machine on holiday: anecdote from Terry: a particular patient (not a participant of this study) tried incognito to take his dialysis machine with him on holiday, in the baggage hold, to a far-away island by dismantling the machine and checking-in the machine parts (unfortunately, he did not receive all the

		parts back and had to ask the engineer for a replacement part).
12	Coordination required for dialysis when going on holiday	• Garry: when going on holiday, with M3, need to arrange for delivery of fluid bags there (48:55,48:19, 48:20, 48:28)
13	Dialysis always in the head when travelling	• Felix: 47:11: "it never leaves you, always in your head, got to get back for dialysis" (when went to wedding in Scotland)
14	Not dialysing if climate not appropriate (which could result in power cut)	• Garry: 48:64: tend to not go on dialysis if stormy outside, as when really windy can blow power out

E.2 Activities within the Home Haemodialysis System

Table E.2: Interaction strategies and issues related to activities within the Home Haemodialysis System

	Strategy/Issue	Example(s)
1	Dialysis causing patient to be fatigued or have symptoms, or decreasing a patient's ability to do things	• Fiona: sometimes gets headaches from dialysis, when done at a certain level, when halfway thru • Jim: 50:8. Treatment makes him very tired. • Garry: 48:8. Wipes you out, tried dialyse morning then go to work, didn't work, tired. • Jim: 52:4. Kidney disease led him to get neuropathy in his right foot. • Kevin: 54:16. "Brain going funny", cannot concentrate while on dialysis. • Adam: Bp gets low during dialysis, harder to do anything, e.g thinking of response to alarm or interacting with touchscreen • David: If you make patient do IQ test during dialysis, will be less than otherwise. Patient's cognitive, reasoning skills decrease during dialysis,less able to understand what's happening
3	Other medical conditions may decrease patient's ability to do things	• alex: 41:25 • Jill: arthritis makes doing fiddly work with syringes hard
4	Other medical conditions may influence how the Dialysis activity is done	• Carl: checked pump speed with Nancy – though higher speed of 350 will get more blood purified, not good for dad because of heart condition, so increased from 300 to 320, as a compromise (between better dialysis and heart condition) • Ivan: he had mini, mild stroke, and a sepsis that caused his bp to drop • alex:41:24 • Erica: 45:3: diabetic (means she has to check blood sugar during dialysis) – a new representation that comes into picture • Ida: 49:34. Polycystic kidneys, bleed, and when bleed cannot use deltaparin, need to use saline • Jim: 52:4: led him to neuropathy in right foot, that's why put sock on foot though you normally wear loose clothes for dialysis • Felix: 47:4. Kidney cancer. • Alex: dialyses in morning to have rest of day, needed to cope with other conditions: "Absolutely, yes. I mean you've got to have a life outside dialysis. Apart from anything, else my other problems force me to go to other hospitals and see other nephrologists. When would I do that if I was dialyzing

		during the day? That's convenient." • Need to remember to use saline as anticoagulant instead of tinzaparin during dialysis before day of operation (possibly for other condition), otherwise bleeding problem: Felix: 47:46 • Need to use saline as anticoagulant when kidneys bleed: Ida: 49:43 • Abi: problem with eyesight. 58:2. Affects positioning of machine. could do with bigger wording. • Eva: 67:18: checking sugar level during dialysis, diabetic. Thinks sugar gets washed out during dialysis.
5	Stay in hospital due to other condition affecting dialysis	• Ivan: (after coming back from stay in hospital): hasn't been filling dialysis chart lately, because he wants to get himself set up and steady first, doesn't even know what his weight is at the moment. Has put on weight.
6	Errors in the Stock Management activity can impact on the Dialysis activity	• Carl: management of stock is important. Have to phone them every 2 months to say what you need. Once didn't check stock upstairs and they didn't have any saline left, had to go to Camden unit to collect some. Now he checks stock to make sure they have everything. • Bea: 43:27. Need to stay in control of it. Once they wrongly delivered two boxes of dialysers instead of two boxes of lines to her. • Felix: 47:6. Must keep an eye on stock, can't afford to run down, or need to do trip to hospital. 47:55: as soon as replaces diasafe filter, orders next one, though this one would last beyond next delivery, always have spare. Because if machine stops because filter needs to be changed, he won't get any dialysis.
7	Effect of Lifestyle Management activity on Dialysis activity	• Garry: 48:12: hard to calculate dry weight, when lost weight, or removed too much fluid. Could be because of either. • Eva: 67:23: drunk more fluid than she should, bad symptoms, fluid in lungs, become breathless.
8	Effect of Dialysis activity on Lifestyle Management activity	• Jim: if dialyse in morning, can eat in evening, whereas if dialyse in evening tend to skip that meal
9	Problem in Technical Maintenance activity affecting patient/dialysis	• Jill: lost confidence in the machine when it was breaking down continually • Beth: 63:6: example of water quality problem, had to dialyse in unit (water quality not good enough) • Several other examples where a patient's machine broke down and they had to go to dialyse in the unit until it got fixed
10	Mistake in Medication Management activity impacting on Dialysis activity	• Observed Nancy tell Bob that he should not have taken a particular pill on the same day that he dialyses, as that made

		his blood pressure problem during dialysis even worse.

E.3 Tasks within the Dialysis activity

Table E.3: Interaction strategies and issues related to tasks, which are not captured in other models

	Strategy/Issue	Example(s)
1	Affective issue of needling being the most problematic part of the activity for some patients	• Fiona: only thing she finds difficult is needling, nothing with the machine. Doesn't like doing it, and has to do it 4x a week. before she had line instead of fistula, which was easier, but less safe in terms of infections. • Ida started needling herself, but then switched to letting her husband do it for her • Reported by some other patients as well
2	Practical issues with needling: locating access and finding proper angle can be tricky, managing with one free hand for lone patients	• Ida: 49:15 • Adam: Sometimes takes longer to connect because of fistula, vein is moving, changed place, harder to find the channel • Cindy: "Initially I started learning how to do it, but then it would be awkward, when there would be some blood spill while connecting the needle. So I would have to hold the plaster with one hand...hard to do the needling yourself."

E.4 Agent-based view and communication channels of information flow

Table E.4: Interaction strategies and issues related to communication channels used

	Strategy/Issue	**Example(s)**
4.	Patient/carer introducing new communication channel to maintain patient-carer communication while carer is elsewhere in the home	• Alex installed an intercom system to be able to communicate with his wife who is downstairs while he dialyses. IMG_1313.JPG • So that Bob can call him in case of a problem during dialysis, while Carl is upstairs doing things, Carl bought a walkie-talkie set. Bob has used the walkie-talkie on some occasions when he was having cramps and neither his son nor wife was in the room. Carl: "Yes, you know, sometimes I go down, my mum's downstairs, to get some tea or something. He calls, yes. He calls to say that he's suffering from cramps. Because my dad panics, so he needs to have it. Somebody always needs to be there; we can't leave him alone, he doesn't like it. If I'm not there, my mum's there, okay. Or if both of us are out of the room, the walkie-talkie is there, so he does call, yes, if he wants anything, yes." • Beth: 62:18: uses buzzer and beeper to call carer to bring drink and biscuits or when there is an alarm. He can sometimes hear alarm himself, but not if he is watching football for example. • Eva: has alarm set, can call son with it, who goes downstairs and does his things during dialysis (like a phone thing, which has a base. She has phone and he takes base with him). 67:13: used alarm set to call son, e.g. last week when she wasn't feeling well, he came upstairs and eventually took her off machine.
5.	Patient having backup communication channel in case particular channel fails	• Garry has an extra emergency landline phone, in case there is a power cut and his digital phone does not work (there are frequent power cuts in his region when it is stormy)
6.	Nurse getting to know of more issues during home visits, in which communication happens face-to-face and at dialysis site	• Nancy considers her visit to the home very important, as it allows her to discover problems that a patient has while using the machine that she would not get to know of otherwise. E.g. she helped Ivan with problems a couple of times while she visited – he didn't call her about these problems as he "didn't want to bother her". On one occasion Ivan's machine was in a wrong disinfection mode (though he hadn't been taught how to do the special weekly programme yet), and he couldn't understand why it kept asking him for a special cartridge.

		• On another occasion, Nancy found out that Ivan was manually turning pump: "I found out that he was manually turning because he'd been pressing prime A and not prime V. But, you know, he wasn't even going to tell me that. He just said oh, it primed all right today. And I said why, what's been happening. Well, I had to manually turn. I said well why didn't you tell me, you know, that's what I'm here for. • Ivan: home sister helped him out with incidents a couple of times when she came around
7.	Blur who should be contacted, nurse or tech (easy when clear that machine has broken down – tech, or when patient's fistula/needling has a problem – nurse. But trickier when it's something to do with the *use* of the machine – could be mistake with lining/priming, in which case nurse can help, or other unfamiliar alarm, in which tech can help)	• Nelly: 55:24 • Nancy: Fluffy area, who to contact, depends on what alarm, whether nurse can deal with it or a technician. Patients are given troubleshooting algorithm to help • Nancy: IV And, so there are some criteria on which the patient can decide whom to contact? IE Whom to contact, yes. I mean they won't always get it right because at the time they tend to, like, if it's something they haven't dealt with before, they might phone the wrong person. But more often than not the technicians can deal with 00:05:12 most problems anyway. But if it's not then the technicians will tell them to contact a nurse. So it depends which alarm. You see, on M2, if it's a technical problem it comes up as a spanner whereas on M1 it just comes up as, you know, sort of a code and you have to know whether that code is for a nurse or for a technician. Well, you won't so what we try to tell the patients is if it's anything to do with your access or the actual general flow, then it's usually a nurse that can help you. If it's just a priming difficulty or something. So you haven't actually gone on the machine, you know, a nurse could probably help you troubleshoot. But if it's something that comes up during dialysis, and it's nothing you recognise, then it's probably a technical, yes. • In some cases, especially for patients using machine M1, patients do not know whether to call the home nurse or a technician for help with a particular problem. It is difficult for them to decide whether something is a handling (e.g. lining and priming) issue or a technical issue. Consequently they tend to phone the technicians, even for issues that are supposed to be handled by nurses. • TERRY: Techs still get most of the calls, even those supposed to be handled by nursing, as they have more knowledge of the machines. But proof of pudding is that anything that is machine related, they are

		calling the techs. Difficult for them to decide whether something is a lining and priming issue or a technical issue, and partially because they phone techs before and know they give them the best chance of getting through it. • Terry: The technician may find that it is a clinical issue, in which case the technician may ask the patient to call the nurse. If clinical, e.g patient may have to get fistula checked in unit.
8.	Machine (M2) helping to decide whether nurse or technician should be contacted	• The design of the technology can help a patient decide whom to call when – on M2, a flashing spanner indicates a technical problem versus a flashing hand indicates a handling problem, while on M1 this distinction is not made. • Fiona calls technician if it's a spanner alarm and nurse if it's a hand alarm which she cannot solve herself. E.g she called technician in incident when machine was leaking and spanner was flashing.
9.	Terminology issues, e.g. patient/carer having own terminology for machine parts, making troubleshooting over phone harder for technician	• Terry: A particular patient referred to the air detector as "bubble catcher" • Neal: terminology biggest problem when learning. 64:21. "Mostly it's how to... a patient's comprehension with the technology. If you give them a different wording there, they... it confuses them. And then, if you say to them, this is similar to what you've learned, sometimes it's better to teach them exactly a new fresh one because they just learned what is it." Example: re-infusion, blood flow rate vs pump speed, UFR. Different terms across machines, and also paperwork. Take months to absorb all this.
10.	Carer anticipating drop in patient's blood pressure through visual symptoms	• When Felix "turns grey", Felix's carer knows he is getting tired, and when he starts yawning a lot, she recognises that his blood pressure is probably dropping
11.	Patient calling out loud for carer	• Felix does not have a special communication channel, but relies on calling out loud for his wife who is downstairs during dialysis when he needs her help • Jill also called out loud in emergency before • same for Ivan
12.	Potential benefits of having channel between DUS and machine	• Tom: 66:2: new machines coming that you can tap into them through their IP. When patient calls, asks them to run him through what they have done, and then talks through what they should be seeing onscreen. If they're in a mess and machine not doing what it's supposed to be doing, get them to start over again, and talk them through it rather than trying to get story halfway through it. • Tom: Communication from home to

		hospital is next big thing. But BT lines to expensive. Having a connection would allow recording of patients' dialysis session details, so that 1) clinician can see details of treatment, e.g. how long patient has been dialysis for 2) technician could see "on" the machine what's the problem, e.g. that the problem is with the pump, based on the flow diagram, as that would be highlighted on the diagram 3) hospital can audit that so many dialysis sessions are really being done by patient, so that money hospital gets for dialysis per patient is justified 4) it opens up other possibilities, e.g. patient could dialyse at home alone, as someone (in unit) could monitor the treatment from distance 5) more patients would go home • Jim: not good that there is no channel for staff to monitor how machines are doing, their state, whether filthy, etc… for infection control purposes. Hasn't been visited by clinical staff since he started. Could network machines, so they could see them. • Nelly: 55:27: Had worry that some patients would just stop dialysing at home and not tell anyone, and nurses wouldnít know, as it happened with CAPD. But doesnít seem to have happened. • David: system in USA to send message to be displayed on machine's screen for patient or nurse, from consultant (so besides getting data about treatment, other way too, push info to machine for patient) • David: In satellite unit, through EUCLid system, consultant can access each patient's machine and change the settings/params remotely and get readings. Same could be done with home patients, but prob is cost for networking. Would need a dedicated modem and broadband connection, couldn't use home broadband for this, and this would cost money.
13.	Limitation of phone as a channel for technician's help in troubleshooting	• Tom: Can people usually resolve the problems via telephone? -> often ask them to re-line
14.	Effectiveness of phone as a channel for technician's help in troubleshooting	• 7 out of 10 times problem fixed over phone: Ted: 57:13
15.	Representation of error message on machine helping other actors to solve problem	• Abi: fact that machine gives message saying what's going on allows nurse and tech to help – they can know what's going on. No misinterpretations, they have better idea of what's going on. Compared to M2. Also no need to just tell patient to come off. Patient reads message on screen, and they can know what to do. 58:29.
16.	Dialysis chart helping nurse to spot problems in patient's treatment	• Nancy: But they are all independent, but they don't want to ask for help. And

		sometimes what is important to us isn't important to them. So by filling in this form they say such and such, and I'll say oh. And that's really important to me and I'll write it down. But to them, they wouldn't have reported it to me. • Gina: On dialysis chart: "Well, if I look at the records, it will help me to know how I'm doing, actually, and then when I go to see Nancy because she doesn't come here every time. Sometimes she'll ring me and ask me how I'm doing and so on. So, I go to her and then when I go I carry this book and what she does is she opens it and writes down... copies everything into her own record and then when we... I do BMI and then we discuss... do blood pressure and everything and then I go."

E.5 Information Transformation & Decision Hubs

Table E.5: Interaction strategies and issues related to information transformation & decision hubs

	Strategy/Issue	Example(s)
1	Recording only first and last dialysis sessions in a week	• Fiona finds the task of filling the dialysis chart annoyingly repetitive, and therefore she does it only for the first and last dialysis sessions of a week, instead of doing it for every session, which is the norm. According to her, it is the trend in readings that is important, and she can still see that with these two readings.
2	Hospital admission due to other condition disrupting information transformation	• After being admitted to the hospital recently, Ivan hasn't been filling the dialysis chart as he doesn't even know what his dry weight is, as he has put on weight. This is an example of an influence of another activity, Coping with Other Conditions, on the Dialysis activity.
3	Patient checking blood results on Renal Patient View to adjust treatment	• Bea checks her blood level on Renal Patient View to assess whether she should take epos on that particular week
4	Difficulty for carer to ascertain state of sleeping patient	• Once, while Eva was watching television, she fell asleep. Her son saw her sleeping, so he didn't check her blood pressure with the blood pressure monitor for a while, as he didn't want to disturb her. Eventually she woke up feeling very sick, and called her son to give her some fluid.

E.6 Shared Goal Structures

Table E.6: Interaction strategies and issues related to shared goal structures

	Strategy/Issue	Example(s)
1.	"Local bit of knowledge" can help technician troubleshoot problem over phone	• According to Terry, they try to mentally build an FAQ tailored to that specific patient. Anecdote from TERRY: sometimes knows that for that particular patient the physical layout is such that a pipe can get crushed under a trolley, and therefore asks the patient to check if that is the cause of the problem
2.	extent to which a helper can provide assistance can be limited	• in the past, Jill used to ask her mum to start the disinfection of the machine while she was on the way back from work. However, when they started having problems with the machine flooding, she stopped asking her mum to disinfect the machine, as her mum only knows how to do the disinfection, and would not know how to deal with the flooding, and doesn't want her mum to be in situation that would upset her • Carl: Has to manually change disinfection mode once a week, for special disinfection with citric acid (programme 1). Does it every Tuesday after dialysis. Takes 1h10 mins, so he leaves before it finishes, but then comes back in the evening, turns machine on, and sets disinfection mode back to programme two, so that next morning his mum can start the normal disinfection. It's too confusing for his mum to deal with the disinfection modes.
3.	Dialysing alone and involving actors in broader SS (for H3 patients, despite H3's policy against)	• Gina: Her neighbor has a spare key to her house, so that if there is a problem while she is on the machine, her neighbor can come in. had incident with problematic tinzaparin. Started coughing and had breathing problem. Had to be taken to hospital in ambulance. Her neighbor called 999 for her and helped open the door to her home. • Fiona: Just in case, has phone number of neighbor, who has key for her main door. • Bea: 43:4, 43:55, 43:56. Sometimes dialyses when husband is away at work, takes measures, e.g. house key on window sill. When she wants to dialyse in morning instead of afternoon, when husband will be here at 2p.m. • Garry: when wife doing shift work. Neighbour on speed dial. • Neighbours having key: Garry (and others): 48:63 • Nelly: 55:14,15. Many patients have had hypotensive episodes, but managed to deal with it, even one who was dialysing solo,

		friend next door came to help. Mentions issue whether to let them solo or not.
4.	Dialysing with only young daughter around	• Alice: Strictly speaking, shouldn't dialyse with only daughter here because of her young age, but she knows what to do.
5.	not having any helper can be problematic (absence of g1 and g2).	• sometimes Fiona gets really bad headaches halfway through the dialysis session. Since she has no one to call to get a paracetamol, she has to take herself off the machine, and then try dialysis next day.
6.	H1 making decision to let patients who live alone go on HH, as patients were being left alone anyway	• Observation of Nancy: at some point, the hospital made the decision to let suitable patients who lived alone start HH, as, the nurse stated that "they found out that the patients were being left on their own anyway…the wife, or whoever, were going out shopping, and so they couldn't impose that someone had to stay with them." The latter is an example of an activity from the broader HS (shopping) influencing the goal g2 of the Dialysis activity
7.	Patient's HS may change, causing HHS to change	• E.g. Fiona had a partner, who could act as a helper when she first started HH, but now they are not together anymore and she is on her own.
8.	other actors from the broader systems can have perspectives on how to do a patient's dialysis treatment that are different than those of actors of the HHS, or even conflicting ones (influencing g3 and g4).	• E.g. Alice states that her new nephrologist is intent on optimizing her treatment more and more, whereas her older nephrologist understood that she had "a life besides dialysis". • Alice: One renal nurse told her she was over-dialysing if she dialysed everyday, not possible to over-dialyse, kidneys work 24/7 • Ivan was told by the home nurse to leave the blood pump speed at 270 ml/s, while another nurse from another unit told him that putting it at 300 ml/s would give better dialysis: "So I've put it back to 300, but they've all got their own ideas as to what it should be." • Carl: nurse at other unit told him that higher pump speed might give better dialysis, consider increasing from 300 to 350. He's going to ask Nancy if increasing to 350 would help his dad.
9.	though clinical staff advise a patient on the patient's treatment, it is up to the patient to implement their suggestions.	• Nancy's observation: As the home nurse stated: "Some patients are advised to increase their hours but they refuse to...You can only give them an advice; if they don't adhere to it, then we can't impose it on them."
10.	gap in understanding of when a patient can/should call a technician for help and when not (gap in g5).	• Carl, who assumed that he could call a technician anytime, once called a technician very early in the morning, as he was getting an error message that prevented him from starting the disinfection of the machine. However, the technician told him that he shouldn't be calling at this time. His understanding was

		that he could call them anytime, to at least give some info if not come out • From the technicians' perspective, it is safer to postpone a dialysis session than to call a technician late at night or early in the morning, when the technician is "probably half asleep and not able to think clearly over a problem"
11.	gap in understanding between a nurse and a technician of whether it is the nurse or the technician who can help solve a particular problem (gap in g4 and g5 combined).	• E.g. once Carl kept getting an error message that neither the nurse nor the technician had dealt with before, and he got redirected to and fro between the two.
12.	a technician's lack of experience can cause stress for a patient or undermine a patient's confidence (arising from g5).	• Jill: "I think maybe sometimes the other technicians there are perhaps not so experienced and they are not so confident themselves, and so, you know, if you're dealing with someone who isn't confident then you can't have confidence in them either." Couple of years ago the problems she had with the water pipe bursting was because "one tech wasn't interested in doing his job properly" • Carl: stressful for carer when engineer doesn't know what problem is. thinks techs/engs don't really know ins and outs of the machine, relatively new to them as well • Ivan: "Technicians not very familiar with these machines."
13.	Actors from the broader HS helping with other activities of the HHS (supporting g2).	• Ivan's son visits him every Sunday to carry dialysis supplies upstairs for the next week, and "keeps the shed turning round so it's all in the right order" • Felix: 47:24: son helps with carrying boxes, he is not supposed to, because of fistula
14.	Splitting tasks in parallel between carer and patient to save time	• P3: 45:10. Was taught machine, table, her. But since both people involved, she does machine while he does table, cuts it down by 15 mins.
15.	Carer talking out loud to patient to double check steps and confirm	• Ida: 51:3.
16.	Improper goal structure, role should be given to patient, not tech.	• Patient changing alarm volume from 4 to 1 everytime. Jim: 52:2. Tech card required to change default. • Gina: Changes duration from 4hrs to 4.5hrs every time. should be able to change default herself. • Abi: complains that cannot change system time on machine (which is 1hr ahead). Need tech card for that, which doesn't make sense. She can change volume level (of alarms). Things in grey she can't change (e.g. system time), things in blue she can change (e.g. volume level). She has it on loudest • Neal: access to change maching setting is via card, nurse has one, tech has one. Patient doesn't. nurse/tech make changes on patient's machine, as it would be

		dangerous to let patient have card according to him. 64:16.
17.	Burden on carer, goals and responsibility for dialysis added on top of other existing goals and responsibilities	• doing day's work then coming home to help with dialysis: Ida: 49:63
18.	Anxiety and stress for carer, if fails to achieve a goal correctly	• Ida: 49:60, feels responsible if something goes wrong
19.	Fact that there is tech or nurse at end of phone would give patient (with carer) confidence to do it on own (or gives self-caring patient confidence)	• Erica: 45:25 (She has carer, but speculating on whether/how she would do it alone). • Many other patients mentioned that too.
20.	Patient wanting to do needling themselves, instead of nurse in unit or carer, to minimize discomfort/pain, as other do not know proper angle. Goal that they feel only they can achieve properly.	• Garry: 48:49, 58. • Gina also reported something similar. • Jim: nurses digging around access, depending on which nurse (other patients reported this problem, only patient knowing proper access, prefer not letting others do it) • Eva: 67:16: patient prefers doing needling herself, occasionally carer does part of it for her. He sometimes finalizes it, easier for him to manipulate the needles from where he is standing. Critical bit, as that's what can cause problems later (pressure alarms). • Abi: 58:7: does needling herself, better if patient does it, results in long er fistula life. Mum just helps by passing her things when going on, when alarms, and stripping machine in end:58:19. 58:11: if alarms, carer mum comes and she will tell her what to do. carer mum knows how to press emergency button. 58:10. E.g. she comes to shake biobags when air alarm. 58:34. And puts plasters over needles and lines. 59:3. Also take readings into chart: 59:5.
21.	Joint problem-solving by carer and patient	• Jointly solving alarm: Ida: 49:66
22.	Nurse learning about some techie problems and helping patient out for some things	• Observation of Nelly: 55:23
23.	Ward staff not being familiar with machine, gap in goal sharing (goal shared after hours, but cannot be really fulfilled)	• Garry: 48:37,48. • Ida: 49:14, 20. Tries to dialyse during day, so they can reach home unit staff in case of problem. • Ida: 49:23: in beginning, had a problem while dialysing in evening, and just lost the circuit of blood, as couldn't call home unit • Jim: 47:29. If Sunday, just comes off and calls home unit on Monday, instead of calling ward • Felix: 47:65: if prob on Sunday, just come off it, wont get any joy from ward. Did that when he had low bp, came off and just went in Monday morning
24.	Inefficient sharing of goals, techs could access data and solve themselves?	• Kevin: 54:5: data from machine sent over internet to KIMAL over US. There, when patient has problem, tech can look at downloaded data to troubleshoot problem.

		But techs in UK told very little, and have to send machine to KIMAL for repairs
25.	Tech from broader system (KIMAL) helping to solve problem	• Kevin: on one occasion he had a strange alarm, rang number he had been given and got phone call back from somebody to do with KIMAL in tech support, gave him instructions, he did these, and it was fine.
26.	No goal for nurse to check on patient at home	• Surprised that nobody's been out to check on them, to make sure they're doing it right, they could be doing anything with it: Jim: 50:19
27.	Going on HH so carer can fulfill goals of caring for other patient as well	• Nelly: 55:9: broader: patients who were not well were coming forward for home dialysis, family member would do treatment for them: e.g. one parent needed dialysis, and other parent had dementia. Better for childrenif dad dialyses at home, so can look after both of them together. • Similarly, Ivan is a renal patient and a carer for his wife who has cancer and undergoes chemotherapy. Ivan fits dialysis around his caring responsibilities.
28.	Patient not comfortable doing a goal and shifting that to carer	• Patient initially did needling, then scared of it, then carer took over needling: Ida: 51:2 • Cindy: initially patient started learning to self-care, but awkward when blood spill while connecting needle, holding plaster with one hand, etc… hard to do it yourself, then stopped
29.	H3 allowing patient who does not fit criteria to go on home haemo, if carer can fulfill goals	• nurse: 55:10. Some patients did not fit co-morbidity criteria, but they were assessed on individual basis, and if they can convince the staff that their carer had the conviction to do the treatment and that it would improve their lives, they would give it a go
30.	Patient/carer liking being on their own when preparing for dialysis, to be able to concentrate	• Bea: 43:21: "But it is a lot to remember, yes. I like to do it on my own. I don't like anyone here, because I have to think to do it, you know? And my husband comes up and chats, and I'm leave me alone a minute. Let me sort this. You know? Or if a friend's sitting with me sometimes, I'll say, hold on, I've got to do this." • Carl: feels confident using the device, but always wary about something going wrong. Feels more confident when alone, than when nursing is watching: can ponder over what he needs to do and think deeply. You make mistakes when people are looking at you.
31.	Patient thinking that carer or other actors of HS are fed up with having the machine at home and the mess	• Ivan: Wife not very happy with having it in the home, it's untidy, but you can't help that. It makes life easier, but wife doesn't think so, she gets fed up with it. • Kevin: says his parents are fed up
32.	Getting helper to start disinfection of machine to save time	• Adam: once called his wife while driving back and asked her to start disinfection, gave her instructions and she did it, not a

		problem for her to do it since then • Carl: Gets mum (patient's wife) to do disinfection. Switches machine on, the RO, and puts on the water lever. With help of stickers.
33.	Helper interacting with machine with instructions from patient/nurse	• Adam: sometimes he can't really use the touchscreen because of low bp, wife helps him with this, he tells her what to do • Ivan: when he almost passed out, wife helped by pushing button to dispense saline. There's a clip that goes to another bottle, she opened that clip and the roller. Wife not trained to use machine. She didn't know what to do, she phoned home sister, who told her what to do. He told her to turn saline on, then he came round a bit, and was able to give her instructions. Once Nancy explained to her what to do, she found it quite easy. Nancy instructed wife to get paramedic, and paramedic came and assessed him. • Jill: Before mum would start disinfection for her while she was on her way back from work, so she wouldn't have to wait for 45 mins
34.	Deteriorating state of patient makes need for helper greater	• Jill: Before when she was quite well, she would dialyse by herself alone in the house. Now one parent is always in the house, doing their own things, but here just in case there is a problem. Before parents would just bring her a cup of tea only. Now parents help by handing her syringes and things, because of her joints. • Gina: would like to have someone she could train to look after her, for later…
35.	Nurse "playing detective" to uncover problems	• Nancy: Because patients are, how can I put it. But they are all independent, but they don't want to ask for help. And sometimes what is important to us isn't important to them. So by filling in this form they say such and such, and I'll say oh. And that's really important to me and I'll write it down. But to them, they wouldn't have reported it to me. So it's just playing detective and getting to know your patient and knowing that what's normal for them and then, you know, getting them talking to you, you find things out when you talk to them.
36.	Patient/carer feeling support of other actors important	• Carl: feels support of others involved in treatment is essential, as the training is limited, and he feels he wasn't trained for that long time. Also machines are machines, and without these people feels he can't really provide a safe service. The fact that these people are there gives him reassurance and confidence. • Many other patients mentioned the same
37.	Patient/carer liking independence that comes with HH, minimal involvement of	• Cindy: likes doing it at home, because others do not have tremendous amount of

	other actors	involvement, she feels liberated and in control of the dialysis.
38.	M3 is portable in theory but requires two people to be transported	• Alice: "And the fact that it is – they claim it is a portable machine, and in theory it is, as long as you've got two of you. Coz I mean it's 50 odd kilos to lift that, so it's a hefty weight. But it is portable, you can take it, I mean we've used it, yeah we've taken it to families and used it in other's people's homes, we've used it in hotels, in caravans."
39.	Patient dependent on carer even for resetting alarms	• Cindy: patient not able to reset alarm due to disabilty
40.	Patient who is not trained on using machine doing basic alarm resets	• Carl: patient knowing basic alarm resets: has patient ever had to reset alarms himself, or press minimum UF button? Yes, he has reset alarms, and pressed minimum UF button
41.	Robustness through carer	• Abi: 59:1. Double-checking of carer allowing problem to be detected. Level was low in drip chamber before they start, usually a sign of risk of getting air alarm during treatment. She spotted that, and they reset the chamber. • Felix: 47:69. Having 2 calendars, 1 patient's and 1 carer's
42.	Carer wanting to be in control (as only they trained)	• Beth: 62:28: she doesn't know to line this machine, knew with M2. Doesn't interact with machine at all. Calls carer if alarm. Beth: 62:28: carer doesn't want her to interact with machine in case she does something wrong, from her perspective, he wants to be in control. His perspective is, he was taught how to use it, she not. Beth: 62:2: carer in control, not letting patient touch machine.
43.	Interface design allowing carer with limited knowledge to intervene	• Abi: mum can help her if passed out by just pressing red cross button. With other machine was complicated, many things to do. But here just press this and it does everything. Allows mum to intervene. 58:9,14.

E.7 Development and Retention of Knowledge

Table E.7: Interaction strategies and issues related to development and retention of knowledge

	Strategy/Issue	Example(s)
1.	Teething issues, making mistakes in beginning	• Alice: Hasn't had anything really with the device (incidents), but when she first had it, because her home nurse was new to it as well and was learning at the same time as her, they had a few teething problems, but that was more like operator trouble where the manual would say do it this way and maybe we'd done it a slightly different way. • Ivan had issues in first few months • Carl had issues in first few months • Nancy tells patients "Especially in the first few months, phone me; that's what I'm here for." • Felix: "But that first, I should imagine, the first three months of having home dialysis is your worst for making mistakes, because everything thatís going to go wrong is going to go wrong in that first couple of weeks. So, that first 12 weeks, or two months, maybe, you know what I 00:54:13 mean?"47:54…" And again, going back to mistakes, the more mistakes you make on it, the better you understand the machine." 47:57. Garry: took 4-5 months to not worry about it. 48:62. • Applicable to many other participants, if not most
2.	Things gradually make more sense at home, overcoming teething issues	• Doing things at own pace in home, then things starting to make more sense (initially overloaded with information) • Ida: 49:41 • Hard to learn initially, then ok with time: Bea: 43:59 • Fiona: Feels confident using the machine, though at first she was scared of getting trained to do it. "at first I wasn't too sure whether I wanted to train to do that, coz I was scared, coz there's a lot of blood going around the lines and everything. A lot of other patients said I shouldn't do it. But I decided to do it because I had done the PD (peritoneal dialysis) at home before, and I was quite _ with that. When I trained with that it was fine, so I thought it couldn't be that much of a difference. It's only that the PD deals with the fluids instead of blood, so that was the only difference really. But everything else was pretty much, not the same, but similar." • Beth: 62:14: learning and getting better over time as you do it, with different machines, Cambridge, M2, M5. Also 62:22.

3.	Patient/carer may themselves train their helper	• Adam is training his wife slowly, who can already disinfect, so that she can help in case of emergency, when his BP is low for example, which hasn't happened so far • Eva: 67:14: carer's wife can act as helper, knows how to administer bolus, learnt by observing him
4.	Patient feeling didn't get explained things during training	• According to Ivan, the nurses in the unit are busy, didn't explain things to him, and just taught him the very basics: "They just told me the basics of how to line it, to start with, and the screen, and I was there for six weeks, but I didn't really learn a lot." • Carl: apparently didn't get taught how to deal with air bubbles
5.	While self-caring in the unit, some patients learn by observing what different nurses do, besides what they are explicitly taught to do (influence of DUS on HHS).	• Cindy observed in the unit that sometimes one can just try resetting an alarm: "an alarm went off and they called the technicians in and they said, you know, try resetting it first because... it's just a little hiccup in the machine." • Ida: 49:6: Wasn't trained on how to do needling, only what to do in emergency, but did it eventually for his wife, who was having trouble at home and losing confidence. Picked it up by remembering what he saw them do. • Jim: 50:20: learnt trick of kicking biobag and shaking it to loosen it to mix properly, saw this in unit • Carl discovered that the quickest way to remove air bubbles was using a syringe, noticed nurses doing that, although he wasn't trained to do it • Terry: shortcuts can be taken and combine to produce effects. E.g when taking out blood line: open door, press a button, it rotates blood pump, you hold pump one end (peristaltic pump) you rotate the pump around and the tubing pops out. Shortcut is just grab the two tubes and wrench it. Physical shortcuts like that. We deal with the consequences, broken doors, etc… IV asks if patients actually do that? Staff, and patients copy them.
6.	Patient getting confused during the training, by seeing different nurses do the same thing differently	• Carl: different nurses had different ways of doing things, and he found this confusing. Someone would say do this and then next time someone would say oh no you don't need to do this. Different ways of priming extra saline line: connect to rest of circuit as shown by one nurse, or just let some saline drop out into bin without connecting to rest as shown by Nancy. He did first one for a while, but then finds second one less complicated. Also thinks maybe first one might have contributed to saline bag emptying and introducing air. • Carl: E.g. one nurse told him to "use as much saline as possible" during the

		priming, which led him to press the pump button again after the machine had finished the priming process once; this led to the saline bag emptying and air entering into circuit, which gave him lots of trouble, requiring him to re-line the circuit at times. He discovered later from the home nurse that if the priming process is done only once, as should be the case, the saline bag doesn't get emptied as the machine is programmed to stop at the right time.
7.	Seeing nurses do things differently but sticking to taught steps	• Cindy: In unit all the nurses do things slightly differently, own shortcuts and things, but they want patient to stick to steps 1 to 10 as taught • Fiona: has seen nurses do other things, but doesn't influence her. They have their way of doing things, she has hers. • Gina: comfortable with how she does it, wouldn't do it any other way, once she has a good dialysis that's all • Jill sticks to the way she was taught by her first nurse. Nowadays they do it in a different method, and Nancy made suggestions, but this just confuses her, she strictly sticks to the way she was taught initially, also thinks that is the simplest way • Neal: worth checking deeper, as would be solution for prob of different practices: They have a patient (experience?) improvement group, which serves to give and integrated/consistent experience to patients, instead of each nurse (who has a specific background) telling a patient some things and another nurse telling another patient other things.
8.	Patient learning by observing a technician implies that the patient may try to imitate what they observed, even if the technician explicitly asks the patient not to.	• Carl observed a technician handle an air bubble alarm by manipulating a tube, or putting paper, to deceive the air detector. The technician told him he shouldn't do it, but still he does it: "sometimes you see the technician doing things, you know; they said, oh, don't do it. But rather than calling them out, they'll do the same thing, you know, I do it. I mean, if it solves the problem, well and good, you know."
9.	Learning by self	• Ida: 49:31. Learnt how to change control panel of pureflow himself, when packs kept changing. They send it to him by courier and asked him to change it, was able to do it. • Alice: "it's learning the little quirks of the machine, like you know, if you do it over ten mins and keep an eye on it it'll be absolutely fine. If you try and do it in the first 4 or 5 it will just alarm constantly, where it's not given itself enough chance to change the pressure guards quickly enough." [referring to the build-up of the blood pump speed]. • Carl: "these sort of things haven't really

		been taught, as I said, as you go on, you know, when things occur you deal with it in the best way you can". lot of things he learnt by himself • IV: So, you were saying that when you didn't clip this thing, the alarm gives a message? Jim: Yes, lower ven alarm. But I didn't know what the lower ven arm was. I know this is the lower ven, it's your venous. The ven, it stands for venous, I know that. But I'm looking at the needle, aren't I? And this door was shut and we just couldn't suss it. So, you do the whole thing, like, you just go and start at the top and you work through all the tubes, you look at everything, open the door, and there the bloody thing was sitting out. I pushed it back in and it was perfect. But then, you remember, see? • Ivan: finds it easy if he follows what it says, but it's only when it comes up with the odd ones that he doesn't know, but he's learning them gradually • Abi: learn many thigns at home that didn't learn in hospital. Continue learning at home. 58:28.
10.	Other hospitals having different practices	• Ivan: Nancy said leave pump speed at 270, while unit z said better to put at 300, to get good dialysis. "So I've put it back to 300, but they've all got their own ideas as to what it should be." • Jim: 50:28. Loses a foot of blood instead of flushing line in the end, as this is a point where air could enter, he doesn't bother, as they never used to in his hospital (this is influence of another hospital, so another category) • Jim: changed dialysis sheet, removed hourly check lines, as in his hospital (st albans), did it only in beginning and end, not hourly. So he does beginning, halfway through, and end. 50:33,34 • Ida: 49:35: saw in Tenerife how they removed both needles at same time, and have none of the sterile pack business, thinks it saves time (but carer won't let her do it) • Jim: 50:32: different suggestions for button holing, originally in hospital and then in home unit • Thinks every hospital is probably different in their procedure and what they recommend: Jim: 50:38 • Carl: unit x was stricter with non-touch technique and hygiene than y
11.	Possible influence of practice from other country	• Alice: Thinks machine is designed for self-care. "I mean they are designed I mean a lot of people using them in the states don't have anybody with them, they do dialyse themselves. And they are designed for that,

		I think it's just here they're a bit more safety conscious." (she sometimes dialyses with only her young daughter around) • Ida saw in Tenerife that they remove both needles simultaneously in the end, instead of removing one at a time and waiting for bleeding to stop before removing the other. She wants to do that too, to save time waiting for each wound to clot, but carer won't let her.
12.	Gaps in the understanding between different actors of the system on the training that a particular patient has received.	• Carl had an incident where the technician assumed that he had been trained on changing the filter at the back of the machine and that he had a spare filter, but that was not the case.
13.	The fact that, in the unit, it's a nurse who does something and not the technician can influence a patient into thinking that they should be doing it too.	• This is one of the things that motivated Gina to learn to change the machine's filter herself: "in the hospital, it's the nurse who does it, not the technician
14.	Patients sharing experiences to build knowledge and confidence to start HH	• According to Alice, she got quite a lot of phone calls from some other patients in their first few weeks of being at home: "They didn't want to ring the nurse, because they didn't want her to think they hadn't been listening to what they had been taught, but just wanted to double check things." • Ida: 49:24,61. Heard from other patient that letting line circulate by itself for 15 mins gets rid of most of air, and that works. Though not what is practised in unit. • Ida: 49:51. Can learn from other patients, also through organized patient meetings. • Gina gets invited to meetings at the hospital to speak to patients who are considering HH and might be afraid. According to Gina, she explains to them how it works, shows them her fistula, and they get reassured. • Alice: 3 or 4 times a year they have a social evening for the home patients, and for new home patients or people who are thinking about it, who can just to along and chat with other people. Alice talks to other patients who are unsure, or they come to see it set up in her home, to see how much space it takes and make sure they have enough room, or to understand ordering of supplies, how much of everything they need. • Fiona: "It was helpful to visit Gina and see how it's set there. I thought if she can do it, I can too!" Conversely, some other patients had discouraged her from doing HH: "…a lot of other patients said I shouldn't do it…" • Prospective patient checking with patient: Bea: 43:38: "I had a man phone up the other day, and he said I understand you're on home dialysis. I said, yes. And he said I wonder if you can recommend it. But by

		his voice, he was very elderly, and he's got needles, and his wife is elderly, and I said to him, for me, it's brilliant, but I don't know for you…" • Beth: 62:23: H4 asking patients to talk to prospective patients. • Beth: 62:23: she talks to patients at the unit about HH. Patients tend to not ask questions when the Sister is there, but then they approach her later on to ask her. Kind of an intimate exchange of knowledge between patients. • Neal: They have a patient (experience?) improvement group, which serves to give and integrated/consistent experience to patients, instead of each nurse (who has a specific background) telling a patient some things and another nurse telling another patient other things.
15.	According to the home nurse, sometimes patients do not contact her when they have a problem or are unsure of something because they do not want to "trouble her"	• Observation of Nancy. Example with Ivan. • Alice: she gets calls from other patients who want to double-check things with her, instead of calling nurse, as they don't want nurse to think they were not paying attention to her instructions.
16.	Artefact with instructions for handling problematic situation not really helpful, as situation was not demonstrated during training	• Issue: Jim: nurses didn't go through procedure of air embolism in unit, they just got the written instructions in the booklet, but these are not clear (lying on back or on side?) Hasn't happened yet, prob very rare, but seems dangerous. 50:26.
17.	Training in unit not reflecting real (temporal and spatial) requirements for doing treatment at home	• Issue: patients not aware of how much time whole thing takes, include all the disinfections, etc. until they start at home. Should be informed. Also not aware of space requirements, water unit space and plumbing (50:22). 50:16: would have been useful to see someone else's home. • Ted: 56:3: At unit, patient doesn't realize 1hr disinfect pre, and 1 hr post. At home, they realize it takes more time with these.
18.	Things not covered in training as they don't happen	• Neal: 64:22: some things may not happen in training, but listed in troubleshooting, e.g. sodium high or temperature high. Neal: some things don't happen in training. 64:21 • Adam trained on alarms in unit, but not for all alarms, only as and when they happen. In unit the problems he had were the same (forgetting heparin and kinking of line). New alarms come up in home, then difficulty. E.g, displacement of bicarbonate line due to crossing with arterial line
19.	So much to learn, forgetting procedures for things that don't happen often or never happen, though learnt these at unit	• Ida: 49:36,42 (example administering saline, notes help) • Ida: for A=0 problem, machine doesn't give alarm number: But that was something that had never happened in the unit, so I'd never, you know…Mr S So, you know when we got to the stage of, we'd done the needling and I'd started to put up the pump

		speed…at that stage we now monitor, are all the numbers as they should be, which was what we were told to do…I suppose you get a bit blasé about it, because then we never have a problem, but then...Mr S You forget what to do when nothing happens. • Felix: when filter had to be changed and he couldn't understand message: "Well, it does mean it, but it was just abbreviated. When I said what it was, and when he came back, because the thing is called [unclear] or something, it's called and it was an abbreviation of it, and it made sense, then, when the technician told me. And then I remembered what I was trained, but because it had been so long, and it was at the back of the machine
20.	Patient having to go through normal duration of training though already experienced	• Alice feels training took far too long for her (2 weeks), because she did home dialysis before and knew the basics, but programme is very strict.
21.	Nurse reviewing patient competencies	• Nancy: Try to get patient to come into unit around every 6 months, to assess their technique, if it has sort of slided. Can also do pre-imposed bloods and assessment that you wouldn't do when they were at home, because at home she wouldn't stay with them the whole time, just put them on and take bloods • Nancy: Patients may need to get competency reviewed, if forgot something, do extra training. Cant expect them to remember everything they learnt, like an ongoing thing. Its like the nurse: if haven't dealt with situation, have to go for a refresher's. patients need refershers to know they're still able to deal with these things.
22.	Learning to self-care by observing nurses and asking questions while dialysing in unit (not officially training for HH)	• Gina used another machine before, and she learnt by observing nurses. She was interested in the machine, and she asked nurses when she didn't know things. She became familiar with the alarms while in the hospital
23.	Interface design reducing requirement for carer refresher	• Abi: 58:10: carer not need refresher on what to do in emergency, as just one button press is required.
24.	Interface design making it easier for patient to learn, no info overload	• Abi: good that machine tells patient what to do, as only learns basics in hospital, otherwise too much information overload. So continue learning at home. And fact that machine tells you what to do supports that. 58:28.

E.8 Individual Knowledge

Table E.8: Interaction strategies and issues related to individual knowledge

	Strategy/Issue	Example(s)
1.	Transferring knowledge from previous machine used, learning in less time	• Abi: 58:41: learnt to use m5 in a week, as had previous experience with another machine, and also finds m5 easier.
2.	Avoiding uncomfortable interactions	• Garry: avoiding pausing during dialysis, not to mess about with it "48:52 • Carl: Doesn't think major error could happen, but there is some ambiguity on things that don't happen often, e.g dealing with BP drop, he is uncertain about that, and asked the nurse to write something for him. His strategy to avoid dealing with that situation, is to come an hour before taking him off, because that's when there's likely to be a problem, and to start monitoring his BP, to make sure it doesn't get to that stage when it can be a huge problem. • Carl feels there is ambiguity on things that don't happen often, e.g dealing with BP drop. Nurse says it's easy, but he's never done it, and nurse cannot show him unless it actually happens.
3.	Workarounds patients developed, how they deal with problems	• Jill: Talks to her herself, first you do this, then do this, then you do this, that way she knows she's not going to make mistakes • Jill: making mistakes when dialysing late due to fatigue, talking to herself to avoid mistakes • Carl: remembering all the steps through having a routine • Ivan: "Yes. It won't alarm now. Well, it might do, and if it does I'll just kill it" • Carl: plays around to find solution to problem. thinks sometimes you have to use your own initiative, e.g taking machine off mode he thinks it shouldn't be in during short clean. Thinks machine is like a computer or community alarms he used to program, so there must be a way to solve a particular problem. When does things you don't expect it to, you troubleshoot it. Play around until you find a solution. Air bubbles incident – open doors, pull some tubes, push it back, close it, and it's rectified. Find own ways of dealing with situation. In blood line sn port incident, tried to solve problem by himself, because they dialyse very early in morning, 5, and do not want to wake up techs at that time. phoned tech eventually, who said shouldt call this time. eventually, carer continued playing around with it and it stopped. it takes "15-20 mins of playing around with it" to get it working. 16:35,17:73. • Carl: When mum tried to start disinfect,

		machine wouldn't go in disinfect mode, kept getting msg bloodline connected to SN-port. Turns on machine, goes to disinfectant, cleaning, yellow (light?) comes up with that message. Played around with it for 20 mins, then somehow got it working. Phoned techs, who explained SN was single needle port, where you twist the lines in, and suggested might be a lining problem. Then he realized couldn't be, as at that point, line isn't even there yet, still disinfect stage. Same thing next dialysis session 2 days later. Played around with it, then started working. Just cleaned everything, doors, needle ports, play with coupling, pull it, shut it, eventually stops. Hasn't happened on wards, unit contacted manufacturer and its something to do with the sensor. The door that you open has sensors in it, that's what he plays with: get a bit of Swipe, clean it, close it, open it, close it, you know, until something happens, yes. (at time of interview they hadn't figured out what problem was) • Alice: Developed workaround of priming line with syringe, instead of letting the machine do it as taught, as she has been unable to get done that way. "In theory you should just be able to open the top and it will draw the fluid up to prime the line. But it never works for me, so I always put a syringe on it and draw it out that way. And that's the only thing, I find that's a quicker way of doing it, coz I find if I do it the way they taught me, which I never did get right when they were teaching me, I just get more and more air in." seems this is related as well, let it get rid of air by itself: "I will always set my _ a couple of hours before I use it. Coz I find the longer you leave it, the more it gets to room temperature which is better as well. And I tend to find it clears the air bubbles on its own. And then once it's done it, it can just carry on and do its own thing, and you can go back to it at any stage." • Carl: Once he couldn't fix air alarm by opening trap and putting artificial tube instead, so he simply unlined and relined the machine, rather than wasting time phoning tech and explaining things he might not even understand (because he knows for sure that relining would work) • Tom: 66:11: there is a link between level of fluid in chamber and air alarm – when level of fluid in chamber is low, and it senses air, it stops pump. But could not clarify exact link. Apparently they should be checking in beginning that chamber is almost full, till where it funnels out.

		• Tom: 66:10: biobags running out with some patients but not others. Not sure what's causing it. Says pump speeds and what it's using flow wise similar, but runs out on machine, not on other. • Beth: 63:5,11: thinks biobag runs off because of selecting pre-dilution option • Beth: When reach point to connect patient, gets alarm, venous pressures, then TMP. Cannot solve it, after spending some time looking around and checking message on screen and suggested courses of action. So scraps lines and starts again. Got it on Wednesday as well. Had to reline everything, then worked. Beth: 62:8: taking her off and putting on again, but didn't work. • Eva: "when for some reason which we cannot explain, either the bicarbonate or the acid for some reason don't flow correctly as they should, or there is a bubble of air or something, and then you get... you know, it tells you conductivity, something wrong with conductivity, and then you shake it, you change the acid, you do what you can, and then sometimes you still don't get the result that you want and 00:40:08 you're in the middle of dialysis and then it can become difficult. Then the best thing is to wash back as soon as you can and then start all over again. But it's very rare. It's only happened, as my son said, a couple of times." 67:31. • Beth: getting conductivity alarm followed by venous pressure high alarm, hasn't been able to figure out cause. 62:4. Presses ?, reads machine suggestions, tried a few things, didn't work. Had to scrap and start over again. 63:12. • Beth: when machine turned off, need to release lines manually by pumping with a syringe at the back (otherwise machine releases them automatically). 62:15,16. • Abi: 58:62: keeping caps to put on needles after dialysis, in case clamp for needles comes undone, to avoid blood spill, and to keep needle sterile if she needs to come off during treatment.
4.	Optimizing strategies patient/carer can do because of knowledge they have	• Kevin: tricked machine into continuing flow when it stopped and alarmed because pureflow stopped supply of dialysate, which had expired during the session. Did this so he could washback his blood and come off the machine, instead of having to lose the blood. his haemoglobin wasn't very good at that time. also he wouldnt have got information on how much treatment time he had done. he connected syringe of saline to dialysate, and tricked machine. "54:19,36 • Beth: 62:19: came off earlier once, when

		she was feeling rough. Not strictly a shortcut. Decrease duration from 4 hrs to 3.75 hrs. • Carl: Sometimes deliberately clamps some of the lines to see if machine alarms, to ensure alarms are working, as he is apprehensive of delaying dialysis of dad • Ida: putting dialyser in place before snapping and tapping instead of when dialyser is reached, like they do in unit, thinks it helps with getting rid of air" 49:69 • Carl: increases pump speed from 150 to 200 while blood is going through dialyser, after connecting arterial, but before connecting venous. Same thing in the end. To speed up things (has to wait a few mins for blood to fill through dialyser). Nobody said anything wrt what speed it should be set to, and he finds 150 quite slow, so he puts it to 200. During dialysis, speed is 300. • Garry: fixing machine himself with hair dryer, problem dialysing in unit, prefers to fix himself, hadn't dialysed for a while. 48:60,53 • Carl: fixed (another) water leak problem himself, cut hose where there was kink and reconnected it to machine: 17:1. Did that to save time, as technician could only come later. • Nelly teaches patients to do disinfection, t-test, and then line.But patients don't always do it. Reasons for doing it this way: 1) This way machine shows steps for lining. 2) to avoid wasting line and dialyser in case t-test fails 3) to avoid getting scalded by opening port during heat disinf. if they forgot and opened wrong port. though technically can do part of lining during disinf (except for port where the hot water would come out during heat disinf) they would need to later on open the port for the priming (so risk is they forget, and open it already during heat disinf)"55:29 • Garry found he could set params to zero to end dialysis prematurely: 48:57 • Alice: she is very knowledgeable about better adequacy with home haemo, and thinks better patient education should be done on the pros and cons.. "I had one particular renal nurse who'd been in the profession for years and years and years, tell me I was over-dialysing if I'm dialyzing everyday, how can you over-dialyse? You know, your kidneys work twenty four seven, you can't over-dialyse, and that's what, that's the sort of mentality that can be out there." • Gina: she has been following the steps,

		except for TMP. When she starts in the beginning, she regulates the TMP so that the red one will not be above the orange one and hence the alarm will not go off. Before she would press TMP in the beginning when requested, but then it might come up again later. What she is doing is adjusting the limits so that it does not go off (it seems to be ok, since anyway when it goes off the only thing she does is just press the TMP button, looks like it's more of an alert than something serious). • Fiona: When pressure alarm, if after checking her needle and line kinks, alarm persists, she changes limits to give her some leeway. Thinks it's fine because it doesn't damage what's happening inside your body. • Neal: 64:20: anecdote of patient who tricked machine, by setting for 1hr, 1.5L, then again, did it 4 times (for a total of 6L, which machine would otherwise not allow). Patient discovered this by themselves. Should have blocked based on total accumulation as well. • Eva: 67:32: shortcut of skipping flow check with syringe sometimes, as she can already see/feel that it is flowing well upon needle connection. Also, it is an artery not vein. Also, even in unit they used to do that. • Eva: 67:25: knows her ideal pump speed • Eva: 67:26: not bothering setting limit for arterial, as it's a negative one. Also understands that venous pressure will decrease during treatment, as blood pressure goes down, less resistance in venous side. But then it will alarm if it goes down too much. • Abi: 58:35: sometimes reduce pump speed when pressure alarm and reset it, ok then • Abi: 59:6: building pressures slowly, gentler on fistula, avoid damaging it. • Abi: 58:32: had microbubbles twice, once had to come off. Frothy in drip chamber. Prob leak somewhere in circuit, couldn't find where. 58:33: other time, mum saw drip chamber quite low, readjusted that and it cleared bubbles. Didn't have to come off. (Model of now checking that everytime before starting – 59:1). In first instance, bubbles not due to chamber, elsewhere in circuit, no chance but to come off. 58:40.
5.	Issues patients face because of lack of knowledge or confidence	• Carl: feels he should have more understanding of the various parts of the machine, what exactly they do. Doesn't have time to read manual. Thinks it's his own initiative to find out, or maybe should have had some theoretical training on what machine actually does. • Influence of wrong mental model developed due to other nurses: Carl:

		Couple of times, while priming, saline bag emptied completely, and air got into system. This creates a long delay, dad lieks to be dialysed early and get it over and done with. To avoid this, he sits there and watches the process, to make sure the bag isn't emptied completely. • Terry: Things like clamping off pressures has been seen before. it reads the pressure here, so if I clamp it off here, I will get through my dialysis without noise. Not knowing if the machine doesn't know what pressure is, it will think thigns are safe at this point and the venous pressure goes up and up until needle pops out of arm or dialyser pops. There are many things even now that can be manipulated from the outside to carry on the dialysis. Machine is quite clever in picking up on situations, but with the right knowledge you can manipulate… • Ivan: he's not very good with instructions and thinks machine is very temperamental. Tells him if he does something out of sequence, and then sometimes doesn't work, like other day it wouldn't clean because he had done something wrong (it seems most probably he would have put it in wrong disinfection mode, according to nurse he hadn't been trained yet on how to change modes to do special disinfection) • Neal: 64:21: "And it takes years really for them really to become experts. And some of them months only. So it depends on how, really, they really wanted to know. And some, they only wanted to know how to operate, so they don't really 12 wanted to know all single wording. As long as they can operate it, that's the main thing for them that they... is to recognise those words, to recognise what that's alarm for. 00:40:18 And then... and when they have an alarm, because it's working all the time all very nicely and correctly, and if there's an alarm, technical problem, they don't recognise, it takes a while for them to respond. And sometimes you really need to respond because of the clotting factor."
6.	Patient's own understanding allowing them to spot problems	• Carl: in incident where water leak was cause of continual stopping of machine after 2hrs of dialysis, decided to take patient off machine, since risk of blood clotting • Alice: Thinks that being more independent and dialyzing everyday, problems are highlighted very quickly. "I think sort of being more independent if you get a problem you *are* more quick to say to them can you sort this out or. And I found when actually I had an access problem, because I

		dialyse everyday, it was highlighted very quickly. When I had that problem I was straight in and having it sorted out, whereas maybe in the unit you'd have one nurse *have* a bit of a problem and then somebody else have a bit of a problem, and it might take half a dozen attempts before they realized that you've got a proper problem. Whereas I think because you're dialyzing at home you can say to them this isn't right, they're straightaway onto it." • Mental model allowed him to rule out tech suggestion: Carl: with blood line sn port msg , called tech in early morning after trying to figure it out on his own but failed, and tech said shouldn't call at this time. got frustrated and said he would speak to tech boss. Dad waiting to be dialysed. Stressful situation. found it patronizing that tech asked him to check if he had lined properly, been lining for a year, and also later realized couldn't be lining problem • Eva: 67:21: knows her symptom of fluid overload, feels bloated up in stomach. Also, her mental model of how different profiles work, and profile 3 agrees with her, intermittent removal. Very sick with other profile, fainted in unit. • Eva: patient knowing own symptoms. 67:22.
7.	Sticking to taught steps as a safety precaution	• Felix: 47:48: sticking to taught steps • Anecdote from Terry: The internal plan representation that some patients have can be vulnerable, according to what the technicians say: "Many of them get by by parrot fashion – I've done this, I connect that, I connect that. That's when it gets difficult, when they've done one thing in a slightly wrong order, they can't step backwards and realize.": Anecdote from technician • Jill: strictly sticks to steps taught by previous nurse, Joy, can't do it differently, it just throws her. Sticking to taught steps as a safety precaution, and to avoid confusion and keep it easy to remember • Fiona: Never takes any shortcuts, doesn't like taking shortcuts and doesn't know of any shortcuts, sticks to the way she was trained. Scared to do shortcuts, in case something happens. So that if something goes wrong, she's not at fault. She did what she was told to do. A bit for her safety. • Cindy: strictly does as told, though she found in unit that different nurses do it slightly differently, have their own shortcuts. Told at beginning to do 1 to 10 as taught. Nurse has lot more training than her, and things go wrong. So if doing it at home, you have to stick to what you've been told by the letter.

		• Carl: strictly following steps taught at the moment, has been told there are shortcuts, such as bypassing full disinfectant process or priming, but not too interested in finding them, as he feels his dad's health and welfare is utmost important. • Adam: follows steps taught, not developed any steps, except for doing priming during disinfection. Does this to not waste any minute, feels machine takes a lot of his time. • Erica: does not line during disinf, follows what stipulated by nurses: 45:19 • Eva: 58:31: saw other nurses do things differently, but sticks to steps she learnt. E.g. instead of connecting line to patient directly from port on machine, they connect arterial and venous together, hook it up, leave it to circulate, then when patient comes, they just connect to patient. She sees it as a potential for getting air bubbles into system so doesn't do it. (has phobia of air bubbles after incident). • Beth: 62:19: sticks to taught steps, lines during disinfection. Wouldn't take any gambles and do shortcut. • Abi: 58:30: doesn't do shortcuts, likes to make sure everything is correct, otherwise potential of getting air in lines, then takes twice as long to sort out problem than if it was done correctly. Sticks to taught steps, though she sees other nurses doing it differently. • Neal: 64:6: if patient sticks to taught steps, wont have problems, if very rigorous, wont happen. Hasn't had any incident so far: 64:9.
8.	Interface Design helping patient to build knowledge/confidence/proper mental model	• M2 shows spanner vs hand. Fiona: Incident where machine started leaking water and she couldn't go on dialysis. Called technician coz she didn't know what was wrong with it. "It just kept flashing, the spanner thing. So obviously there's something wrong, that's how I know when there's something wrong with the machine. So it won't prime. Every time I primed it it started leaking more. So I called the technician and apparently there was a hole in one of the tubes inside, actually inside the machine. The technician said the tube it happens now and again, it wears out, and then it has that little hole inside, coz of all the, when you heat disinfect it it stretches and because there's a plastic tube so it gets a hole in it sometime." • Fiona: Can handle other normal alarms like venous pressure, arterial pressure. Calls technician if there's something wrong with the machine or cannot understand what alarm is about. Calls nurse if it's

		something wrong with her, with the fistula or can't get needle in. "if I don't know what's wrong with it then I'll phone the…umm normally when there's something wrong with it, it's normally just like a number, letters that come up on the screen. So I have to take down that number and whatever letters is there and tell them. And then they'll tell me what's wrong or if they can't if I can't deal with it on the phone while I'm on the phone with them, they'll come and fix it." • Fiona: "P: not if it's a spanner, I don't understand what to do. If it's a spanner, it means there's something actually wrong with the machine itself. Like inside the machine. But sometimes it alarms and then it has the hand sign and I'll press it and it will tell me what's wrong, like if I've forgotten to connect one of the tubes without like, first I have to prime and then forgot to connect the draining tubes into the dialyser, if I forget to connect some of the tubes it will alarm and tell me that I've forgotten to connect the tube in, or you forgot to unclip. Coz sometimes when you're priming you forget to unclip the water to go through, alarm that says no water going through. So you could unclip it so the water is released so it can go on the machine and prime." • Beth: 62:16: doesn't really have to think about it, as machine tells you everything, just follow the steps • Abi: 58:41: user-friendlier machine taking less time to train on
9.	'Mental model' in which machine is very safety-proof giving them confidence	• Ivan: you can't really go wrong with this, and it won't let you go on unless it's right. Gives him confidence, won't work if it's not right. • Cindy: quite reassuring at the back of your mind that if you did something wrong the machine would tell you • Jill: Stress, and losing confidence in machine: 25:18, 25:60 • Mentioned by many other patients too

E.9 Values and Preferences

Table E.9: Interaction strategies and issues related to values and preferences

	Strategy/Issue	Example(s)
1.	Avoiding wastage	• Re-using bicarb: Bea re-uses bicarb instead of discarding after first use, means she can run out of bicard during a session, and therefore she keeps spare one next to her - carer could get for her, but sometimes not here, so has to cater for that too. 43:58,43:60
2.	Going for convenience	• Jim: just loses 2 feet of blood instead of flushing line at the end, as would have to deal with not letting air in, etc.. "50:28
3.	Optimising on peace and comfort	• Jim: key thing is has to be stress free, that's why he chose living room, nice view on garden "52:3 • Alice: doing dialysis in verandah, heating machine in winter, and stocking dialysate in winter • Terry: Things like clamping off pressures has been seen before. it reads the pressure here, so if I clamp it off here, I will get through my dialysis without noise. Not knowing if the machine doesn't know what pressure is, it will think thigns are safe at this point and the venous pressure goes up and up until needle pops out of arm or dialyser pops. There are many things even now that can be manipulated from the outside to carry on the dialysis. Machine is quite clever in picking up on situations, but with the right knowledge you can manipulate… • Pre-empting alarms: Gina: adjusting TMP before alarm goes off: She moves the limits so that the orange and red bars do not touch, she "separates" them. Then there will be no alarm and everything is working. She doesn't know exactly what that does. But since the machine continues working after adjusting this, it doesn't stop, she assumes that it must be ok to do that. "If it's dangerous it will stop." "if it's something serious, there's nothing you can do to make the machine start". • Fiona same as above • Several others same as above

E.10 Physical Layouts

Table E.10: Interaction strategies and issues related to physical layouts

	Strategy/Issue	Example(s)
1.	Machine as intrusion into HS, patient having a secluded "hospital" room for dialysis	• Carl: thinks machine does not fit in a home, an intrusion, not adaptable to the home, and try to conceal it as far as possible, thinking of putting a curtain around it when finished so don't see it • Felix: "I call it my hospital room...When I leave this room, I shut that door and I don't come back in, if I can help it" • Bea: "when I finish dialysing, I shut the door, lock it, and it's out of the way…I try not to let them see it because I don't like to involve everybody. It's me. I have to put up with it, and I've got to think of my family. They don't want to see me on it. They don't want to see it around if necessary…" • Abi: 58:24: likes that she has separate room for dialysis, so doesn't need to look at machine on days she is not dialysing.
2.	Patient calling out for carer/helper, who is on different floor of house, for help	• During an incident in which Ivan was passing out, he had to call Helen upstairs for help. • Jill: "I remember once when I was having problems I did feel I was sort of passing out. You know, I could feel myself going and I called out to my mum, or something, I think. And she heard me, so she came up…" • Felix calls for his wife who is downstairs
3.	Patient dialysing in carer's office, so carer can work while looking after patient	• Instead of dialysing in a spare room upstairs, Ida dialyses in her husband's office, so he can simultaneously work and attend to problems with her dialysis. IMG_1386,87
4.	Carer coming upstairs/downstairs at a certain point to stay within communication reach of patient (maintaining situation awareness)	• Alex's carer comes upstairs a bit before alex finishes dialysis, to check if he is alright, and then plays computer games in the room next door, until alex calls her to start taking him off the machine • Carl's carer comes downstairs an hour before the end of dialysis to check on Carl, as that is when Carl usually gets cramps, and then sits nearby in case any problems happen • Eva: checking on patient every now and then. 67:13. • Abi: 59:2: mum next door watching TV while she is dialysing. Can hear alarm or hear her shout. E.g. Anneli shouts for her when there is alarm due to air in biobag, then she comes and gives biobag a kick, and then it's fine (she can't kick biobag herself while she is seated on chair during dialysis, obviously)

5.	With M3, not hearing the machine alarm during fluid batch preparation may mean the patient not being able to dialyse when desired	• Ida has her machine on the ground floor and her bedroom on the first floor: "The other day…just as I was going to go upstairs it started to alarm. Had I not heard the alarm, I wouldn't have heard the alarm upstairs, it would have just carried on alarming throughout the night and it wouldn't have made a batch up for a start in the morning, which is what we had intended"
6.	Machine noise causing issues for the HS	• Adam tries to finish dialysis early in the evening so that the machine's noise does not disturb his young son's sleep (in adjacent room?) • The motors and fans of M3 make noises at regular intervals even when it is not on, as the machine maintains the dialysate fluid at a certain temperature, and it can be annoying for Garry to hear these. Also, when the machine is preparing a batch at night, it makes a whirring noise which his next door neighbour can hear • Kevin: 54:4: not putting machine in bedroom again, as it makes noise, even when off, and he has to sleep with that (computer thing makes the noise). Also 54:25,26: machine makes whirring noise every now again all the time when there is a batch in there, to mix batch and keep it at temp. It wakes him up when he's just drifting off to sleep. On one occasion when he was preparing batch overnight, slept in his room, had awful night's sleep: 54:27
7.	With all machines except M3, the place where dialysis is done strictly limits the patient's activities in the HS during dialysis, as the patient can only dialyse in that one particular place	• Fiona: "once it's plumbed in one space you can't move it around, and I can't bring it in here and use it. I have to be in the bedroom because that's where it has been plumbed in…I can't go anywhere for 4 hours while I'm on it."
8.	Changing dialysis site with M3	• Alice: taking (portable) machine upstairs to dialyse at night
9.	Dialyzing in the bedroom can create issues for patients and their families, by conflicting with expectations of the bedroom as a part of the broader HS	• It causes a privacy issue for Gina, since people such as the home nurse, the technician and myself come to her bedroom because of the machine being there • It causes an inconvenience for Adam's wife, who is pregnant, and has to go rest in her son's bedroom when Adam is dialysing in their bedroom • It causes psychological stress for Kevin: "It's a pain seeing it all the time. And every night, to be fair, I come in here and think, oh, I've got to sleep with that blasted machine" IMG_1463 • Ivan: Wife thinks the machine makes bedroom untidy, a mess. Ivan: "machine is bulky, very bulky, when you think this is in the bedroom next to you all the time"
10.	Patient dialysing in an atypical but nice	• Alice dialyses in her verandah, which

	environment, and then coping with resulting issues	overlooks her garden, as it's a nice environment. Consequently, she has to remember to leave the heater on in the verandah in winter, because "when the machine gets to a certain temperature, it struggles to maintain itself and starts to alarm and things like that" • Jim dialyses in his living room, which has a nice view on his garden. When hosting guests (an activity of the HS), he adapts the room for that activity by setting up a wooden partition to hide the TS. IMG_1402,03,04
11.	Spatial requirements of dialysis hampering activities of the HS	• Since Felix lost a room to dialysis, it's harder for him to have his grandkids stay over. He also had to convert his shed into a medical storage room.
12.	Restricting access of certain actors of the HS to the dialysis site	• Garry has a stair gate to keep away his dogs and also shuts the door • Ida put a lock on the door of the dialysis room because of her grandchildren
13.	Striking a balance between having dialysis supplies close to the dialysis site and protecting aesthetics of the HS	• Carl: main supply kept in attic upstairs, in boxes, while smaller supply kept in cupboard in room. It's quite a climb to the attic, but not putting boxes in room as doesn't want it to look like a clinic.
14.	Bringing supplies indoors during winter	• Ida: 49:43: need to bring sacks indoors from garage during winter, as will be too cold otherwise and machine won't prepare batch
15.	Dialysis supplies spreading all over the HS	• Kevin: 54:30: supplies not only in his room, but upstairs as well, space that parents would rather use for other things, parents fed up with clutter. 54:30,31: would like to have a room in which put all stuff, go in dialyse, tidy up then come out • Even invades refrigerator: Felix: 47:66 (epo) • Jill: Kitchen was small, extended it to keep stock in kitchen on the shelf. Had it for several years, but it's not nice, it's messy, stock is massive.
16.	Delivery of more supplies than needed, problem of where to keep them	• Bea: 43:35. Delivery brings month's supply (in excess), problem of where to keep all of it. Had to turn computer room to storage room.
17.	Ordering only required numbers of supplies	• Jim: orders only amount required for delivery, not default amounts, as not enough space to store, counts how many needed till next delivery. (has about two spares, but seems he ran out the other day? see 50:17, 52:8)

E.11 Arrangement of Equipment

Table E.11: Interaction strategies and issues related to arrangement of equipment

	Strategy/Issue	Example(s)
1.	Besides facilitating access to equipment, another reason some participants keep all equipment in the dialysis room is to protect the aesthetics associated with the broader HS, that is not having medical things spread out across the house. In a sense, all the "clinicalisation" has been done to the room where dialysis is done, so that the rest of the home is spared.	• Carl keeps the main supply in the attic upstairs in boxes, while the smaller supply is kept unboxed and "hidden" in a cupboard in the dialysis room. • Ivan: keeps everything in bedroom (on chairs, on nearby furniture, and in drawers) so it's not spread over the house, so there is mess in room so that no mess in rest of house. Like a self-contained, area for dialysis "What I do, I go in and shut the door and I don't come out for three hours" • Kevin mentions he would like to move house and have all dialysis stuff in a separate room • Jim: 50:13. Machine in living room, but using partition to change look of room when required. Also 52:3: supplies kept in cupboard, out of view.
2.	Using parts of the TS as pieces of furniture	• Adam keeps dialysis chart, blood pressure monitor and manual on machine • Fiona keeps desk lamp on it, so she can have more light while preparing for dialysis. Also keeps cleaning liquid on top of machine. • Carl: Antibacterial wipe kept on top of machine • Ivan keeps cup of tea on water unit • Adam: IMG_1318. Using machine's surface to lay out equipment
3.	Using physical surface of machine to support activity	• Gina sticks plasters on the lower edge of the machine's screen, so she can easily retrieve plasters while doing the needling • Ivan: puts plasters on lower edge of screen, with a pad attached. He says that in unit, nurses stick plasters on a table in front of them during needling. Here no table, so he sticks them on screen. Also it makes it simple for him to turn round and get the plaster to put on his arm • Fiona also does the above
4.	Some participants make sure they have extra medical supplies within hand's reach	• Cindy: had the experience of a syringe break during use, so she keeps spares at hand • Important for self-caring patients who have limited mobility due to other conditions, e.g. Jill • Important for self-caring patients who are completely on their own, e.g. Gina • Alex: IMG_1307. Spare box. • Bea: 43:25. Extra tank next to machine, in case first one runs out during dialysis (as she re-uses until finishes). And wants to avoid having to take herself off as she

		hasn't done it yet, need to read instructions for recirculation. • Felix: spare diasafe filter and spare disinfectant on standy. 47:23. • Abi: 59:10: spare biobag and saline close by, if need to change biobag due to air, if need to give her saline in emergency.
5.	Self-caring patients lay everything around them on the bed before starting treatment, including spare supplies, telephone, mobile phone, blood pressure monitor and tea flasks.	• Gina: puts everything around her before starting so she doesn't have to move later on, including the ones she will use after the treatment. Extra supplies in plastic bag. E.g if she contaminated the needle, she can change it. Telephone too, in case problem and she needs to ring, both landline and mobile, and in case Nancy calls her. Bp monitor, if she feels unwell, connects it to check bp. Tea flask also. She also has all the telephone numbers ready (water, electricity, technician, emergency) • Also when carer away: Bea: IMG_1324. House key on window sill. For when husband is away. Also drinks and biscuits: 43:47.
6.	Patient with restrictions in movement keeping all things next to her	• Jill: has arthritis
7.	Having an emergency bag ready, in case someone who doesn't know where he keeps things has to help him	• Felix: IMG_1362. Bag with emergency supplies/equipment prepared and kept there by patient, in case someone else (who doesn't know) where he keeps his stuff needs to intervene
8.	Limitations of the physical layout in which equipment is arranged and manoeuvred in the home, as compared to the dialysis unit, can create new extraordinary situations for patients and carers.	• Adam: incident where his stretched arterial line displaced concentrate line, as the two lines were crossing each other. Led to new alarm, took him a while to figure cause of problem. In unit, layout is different and lines would not cross. Also in unit, arterial line is not stretched as it is in his setup at home. "[in unit] doesn't happen this thing because it's more comfortable. You are closer to the machine, and the line is not stretched like in my case here at home. So if it's not stretched then you can move, and it won't interfere with others." • Cindy: Once probe that sits in concentrate got knocked and pulled slightly out (same issue as above). "Yes, I think I knocked it while I... because there's such a tangle of wires and you can move one and it can knock another one out." • Similarly, Ivan reported that, once, a tube that got crushed under the wheel of the machine's unit, while the room was being cleaned on the weekend, resulted in an unfamiliar alarm message the next time he dialysed. It took him an hour to figure out the cause of the alarm. • Kevin: 54:7. Things that lock lines can get twisted and undone, e.g. when he is snuggling up into his duvet (due to dialysis

		cold) and these can be rubbing between sheets. Then just takes a yank and it comes out and blood pours, when he moves his arm or rolls over (happened twice, once when his gf was with him) Kevin: 54:7: locks on lines get unscrewed (due to rubbing with blanket sheets) and then it only takes a yank and line comes out, blood pours out. Happened to him once, and caught it undone twice. • Carl: Incident when hose at back of machine burst (connecting RO to machine), and water was coming out. Happened because of movement of machine, it got a kink and it eventually split open.
9.	Moving around while dialysing	• Kevin: 54:17: sometimes moves around his room during dialysis and does few bits, knows hospital would disapprove and it's dangerous
10.	Difficult to not move arm for so many hours, and moving can result in kinking	• Ida: 49:25: difficult to not move arm for 2.5 hrs, and moving can result in kinking, carer thinks patient being too relaxed about it and doesn't pay enough attention to arm • Felix mentioned something about having to stay in same position for 4 hrs
11.	Using adjustability of chair in low bp situation	• Importance of chair being adjustable, helps in low bp situation: Felix: 47:61
12.	Having a designated "stationery area" where dialysis measurements are kept	• Gina: has a "stationery area" where she records all her venous pressure, arterial pressure and everything else.
13.	Restricted space for technician to operate on machine, opening and doors and working on it.	• Terry (while at Jill's place): Some patients have even smaller space for dialysis. Some machines allow technician to work from one angle only, while others need technician to access them through 4 different angles
14.	Arranging equipment spatially according to temporal order of use	• Gina: New sterile pack, that will be used first when coming off, is on top, whereas old sterile sheet, which will be used later while disposing of the needles, is below
15.	Having extra emergency button right next to patient for dispensing saline	• Beth: there is an emergency button next to her on chair, connected to machine. It gives her some saline. (her machine is away from her, so she cannot interact with machine, that's why extra button is needed). 62:27.
16.	Importance of having machine manual at hand for M3	• With M3, it is crucial for patient to have someone who can hand manual to them, or for lone patient, to have the manual within arm's reach, as that machine's interface only displays an alarm number which needs to be looked up in the manual.

E.12 Physical Ergonomics

Table E.12: Interaction strategies and issues related to physical ergonomics

	Strategy/Issue	Example(s)
1.	Components hard to press	• Adam: finds clamps of lines too hard, hard for ill person, specially with low bp, to clamp. • Alex: No, I sometimes I find the buttons hard to press. You have to really put some 00:42:45 pressure on, and when youíre lying down thatís sometimes difficult. But the reason they do that is to make sure in the hospital that if anybodyís walking past a machine and falls onto it, or anything stupid happens like that, the buttons are too hard to press to, you know, make it go wrong. So there is a reason for that. And as I say, I sometimes find it hard. IV But you have to apply a lot of pressure? 00:43:11 IE Yes. Pile on pressure, yes. And, you know, Iím not a young man anymore, and because I donít have a full intestine I canít eat a proper diet, and so possibly because of the heart attack as well. I donít have very much stamina or strength anymore. I mean I canít even change a light bulb, for instance, itís just too difficult for me."41:25
2.	Coping with fiddly work	• Bea: "You're not taught to use scissors in the unit. You're taught to do it all by yourself. But I had a fall about six months ago, and I had a plaster on it, and since I had that, I've got a weakness in the thing and I 01:21:34 can't pull everything like I should do. So when you see [Nelly], tell her I was doing it right. See, I don't cut corners because of hygiene. You know? Some people want to cutÖ Mind you, that was the problem with my dad. He used to cut corners when he did use the peritoneal and he had to go in a couple of times because he didn't know how to IV The reason I was asking about that is sometimes the fact that people cut corners means that maybe the design of the machine could improved.01:22:20 IE Yes, hygiene. They canÖ you want to get off quick and go. Yes, my dad was. He used to just rinse his hands, but you're supposed to wash them up to your elbows. I don't know. Maybe it is. I don't know. I wouldn't say that. I'd just say hygiene.""43:66. uses scissors because of her problem, possible conflict with hospital hygiene policy • Jim: opening package of a supply is most difficult thing "52:6 • Nelly: For patients with arthritis probs, connections on M3 can be tricky, fiddly,

		quite small "55:20. • Jill: recently has problems with joints, sometimes when opening packs or unscrewing things her fingers are so bad she can't do it, has to ask someone else to do it for her. other day she put her syringe in and didn't screw it properly (her fingers get bad, sort of fiddly work and she doesn't do it properly, or she's tired and can't concentrate), so when she pulled that out all this air was coming, and she wasn't thinking and she pushed, and you shouldn't push when you've got air like that (nothing happened, air detector in machine)"
3.	Participants try to adjust the position of the machine relative to the bed so that they can easily reach the machine's interface and read displayed messages, from their position on the bed.	• Ivan: screen is close to patient, and angled so he can read it from his lying position • Fiona: Moving machine screen close to her on the bed
4.	Reach problem to machine	• Adam is positioned quite far from the machine, which means he has to get up from his lying position and stretch to reach the machine's touchscreen. Takes quite an effort to get to it in case of alarm. This is worsened by the fact that his machine does not have an extendable arm to allow convenient positioning of the screen (there is an option to have the screen on a flexible tube, more expensive). Says this setup is for unit, not home. Also, the machine was on the other side of his fistula arm, causing the arterial line to be stretched more than normal. He mentioned trying to make arrangements to get the machine on the other side of the bed. • Nelly: Had problem with some patients, as chair not high enough to reach machine. Knows that some other home machines have retractable screens, so patient can reach it. "55:1 • Cindy: Eric paraplegic, hard for him to lean over to the machine to reset alarms, and through leaning movement he can set off alarms again • Abi: 58:54: machine could be closer to you. M2 had arm, easier to pull screen towards you. • Alex: IMG_1309. Chair control (can be reclined). 42:1. Mentions problem with reaching M4 from reclining position. So he sits on chair, programs machine then reclines chairs once dialysis has started.
5.	Reach problem to patient's access site	• Ida: hard for carer (to reach for access or inject something) with current dialysis chair, not adjustable like in unit"49:27,51:1. Chair should adjustable, like in dialysis unit, so it can be suited to carer's position (when doing the needling, has to bend down)

6.	Even in cases where the carer is the primary user who interacts with the machine, the positioning may be adjusted so that the patient may optimally read the screen and interact with it.	• According to Carl, Bob, who does not do his treatment himself, likes to have the machine close by so that 1) he can see the treatment time remaining displayed on the screen 2) he can press the alarm reset button in case of a minor pressure alarm and 3) he can press the "Min UF" button if he starts feeling unwell (which would suspend fluid removal). He has reset alarms and press the Min UF button in the past.
7.	Participants using M2 reported liking that the machine has an extendable arm for easy positioning of the screen, which allows them to reach the interface even while lying down on the bed.	• Fiona: likes that you can move the screen with the shrivel, so you can see it easier instead of having to stretch up, unlike other machines from the same manufacturer where the screen is on the machine. • Gina: likes that you can adjust the position of the screen, with the shrivel, unlike the machines where the screen is on the machine itself • Jill: likes that control panel is on movable arm, and not on machine like before, so she can bring the arm around even when lying down to see what's happening. Before you couldn't see.
8.	Perception	• Abi: 58:55. Problem with perceiving values on screen.

E.13 Space and Cognition

Table E.13: Interaction strategies and issues related to space and cognition

	Strategy/Issue	Example(s)
1.	Using space to support the planning and preparation for the dialysis session	• Jill uses the area around the machine as a sort of staging area, putting dialysis supplies such as the bicarbonate cartridge and the concentrate canister next to it one by one. • Bea: uses surface to lay out things while she prepares her supplies for tomorrow's session. 43:26.
2.	Use space to provide cues that remind them to perform some steps	• Adam, who in the past forgot to use the anticoagulant before starting treatment, lays down everything on a table before starting to help him ensure that he uses the anticoagulant – there should be nothing left on the table if he did all the steps.
3.	Broader HS can interfere with a strategy that a patient devises to facilitate their interaction with the technology.	• E.g. once some random objects on the table, typical of the home, occluded the anticoagulant, preventing Adam from seeing it, and he forgot to take it. This resulted in blood clotting in the extracorporeal circuit and him having to scrap the lines and start over again.
4.	Having separate tray for coming on and off	• Alex: IMG_1308.JPG. separate trays for ON and OFF, marked as such. Whereas some patients re-use same tray, and prepare it for coming off. • Bea: 43:23
5.	Keeping one hand for trolley and one hand for doing hygienic things	• Bea: 43:67
6.	Knowing where a particular equipment is kept to retrieve it easily, through special spatial arrangements that bear meanings to patient.	• Alice keeps different types of supplies in different drawers • Garry: IMG_1372,73. Separated by type • Felix: IMG_1355. supplies segregated by type in drawers. 47:40. • Bea: IMG_1321. Supplies segregated by type. 43:23. • Jim: 50:12. Jim: IMG_1399,1400. Supplies in cupboard and separated by type. • Carl: Trolley has 3 shelves. Each shelf has a compartmentalized tray, each compartment containing a type of supply, e.g one for syringes, one for dressings. In supply wardrobe as well, supplies grouped together by type. IE Yes, I know where things are. You know, like, you know, the sodium is on the right-hand side; then I've got the dialyser at a certain place; I've got the fistula packs in certain places. I know where the syringes are, you know • Ivan: two drawers in a set of drawers for keeping supplies, top one for plasters and wipes, second one for dialysers and syringes. • Jill: keeps supplies in little baskets, each

		basket for one thing, e.g one for renal packs, one for dialysers

E.14 Physical Naturalness

Table E.14: Interaction strategies and issues related to physical naturalness

	Strategy/Issue	Example(s)
1	Way buttons are laid out, in vertical order, indicates sequence in which buttons need to be pressed, steps that need to be performed.	• Alex: 42:6. • Carl: mum relies on something similar to know order of stickers for starting disinfection
2	Marking fistula access point with pen	• Ida: 49:7.
3	Marking which tray is for what	• Alex: IMG_1308.JPG. separate trays for ON and OFF, marked as such, emergency as well
4	Patient referring to coloured markings on machine and parts when lining circuit or connecting parts	• Ivan: machine (M1) points out what you have to do, it's all drawn around, behind the pipes you can see there's a red and blue line, and it shows you where to put them in • On M3, Alice finds it helpful that the fittings on lines and on the machine are colour-coordinated (green for dialysate line and yellow for waste line)
5	Physical forcing function helping patient	• Alice: cartridge for M3 will fit in the machine only in the correct way: "And then here [points to holes on cartridge plank] you've got like the holes which relate to the centre so you can see where – it'll only go in one way, there's only one way of putting it in. [fits cartridge in machine]. If it's not fitted properly, it won't let you shut it down and lock it."
6	Limited colour-coding making it harder to distinguish ends	• Jill: before, the dialyser caps for M2 used to be completely blue and red to help distinguish between the arterial and venous ends, now only a small section, making it harder to distinguish

E.15 Situation Awareness & Horizon of Observation

Table E.15: Interaction strategies and issues related to situation awareness & horizon of observation

	Strategy/Issue	Example(s)
1	Visibility of blood's movement	• When about to connect the line from Bob to the machine, Carl does not wait for the alarm, which is triggered when the blood reaches a certain point in the circuit to indicate that the blood pump should be stopped and the patient should be connected to the machine. Instead, when he sees that the blood is close to reaching that point, he already proceeds to switching off the blood pump and connecting the patient. • Gina: forgot to clamp something the other day, and she started the machine, but her blood wasn't going around the machine, so she realized she hadn't clamped something.
2	Visibility of blood's colour	• Once, when Gina had an incident while connected to the machine, due to a defective batch of anticoagulants, the unusual blackish colour of the blood indicated to her that something was wrong. • Bea: 43:68. When re-infusing, colour helps know when to stop. • Carl: (same as above) "I remove the blue line when the line is a rosy colour…obviously the blood's very red – dark red, so when it's become rosy…"
3	Visibility of kinks in lines and clamps on lines (many participants reported that, when they get a high-pressure alarm, or when they see on the display that the pressure quickly jumps to a very high value, the first thing they do is a visual scan to check the states of the lines and clamps.)	• Alice: "Last night within a few seconds of being on it was up in the 400 – and it was only when I glanced around I realized I had left the clamp on to me, so it was a case of silencing the machine, letting the pressure settle right back down, and then just starting it again." • Fiona: pressure alarm: check needles, and line for kinks, and see if line caught in something • Adam: Saline was clamped off, tube in blue compartment was a bit collapsed in. N asks him what he thinks is wrong…then gives him a hint, and he removes saline clamp.
4	Visibility of presence or absence of air bubbles in lines	• On M2, depending on where the air bubble is, the patient can either just tap the line to get rid of it or turn a knob to raise the blood level in that particular section of the circuit and thereby get rid of the air bubble. Gina looks at chamber to see if blood is below a certain line (because there is a pipe). If so, she turns a knob (that can be used to either increase or decrease the level of blood in the chamber) to increase the level of blood and that stops it. Otherwise, she can sometimes see

		the air bubbles, and just taps it, and everything is ok (then you press the alarm's red flashing button, and it stops) • Seeing bubbles going through when snapping lines to remove bubbles: Garry: 48:9. • Bea: 43:20. She forgot to connect red and blue lines to dialyser, and though machine did not alarm though something was not correct, by seeing bubbles and hearing clicking sound, she knew something was not right. • Cindy: when air bubble alarm, opens door to the trap, and can see bubble in there, taps tube and it rises and gets taken out of system • Alice: Know when there's no air by looking at the lines • Jill: on one occasion knew there were air bubbles because she could see them
5	"Normal sound" of the machine	• Gina: knows the normal sound of the machine. So if she went on the machine but forgot to unclamp something, she will know from the sound that it's not the normal sound and that something is clamped, and she will find it and open it. • Bea: 43:20. She forgot to connect red and blue lines to dialyser, and though machine did not alarm though something was not correct, by seeing bubbles and hearing clicking sound, she knew something was not right.
6	Issue: machine's noise preventing awareness of what's going in rest of home.	• Bea: 43:39. Cannot hear doorbell, has to put TV on loud to hear
7	Visibility of colour of dialyser	• Jim: if dialyser not nice and pink top to bottom, means there might be a blockage somewhere (if it's half pink and there's still water in it, or still white) could be dialyser is dodgy, needs to be changed. 47:17.
8	Seeing cloudiness in drain line to know bleaching needed, instead of doing it regularly	• Kevin: 54:24
9	Seeing pressure graphs on machine's display	• Alex: 41:20. He had forgotten to connect dialysates up, but apparently saw pressures were too high, and then noticed he had forgotten to connect dialysates. (according to him, apparently machine would have still started?) • Felix: 47:27. Looks at pressures to monitor what's going on. "So, then I just keep an eye on this all the time. If this drops or that goes up, then I'll have to spread the alarm....See, that's dropping a bit now, on to this marker? What I'll do now is, I'll bring that down. See how it's… if you leave it too long, it's going to alarm. What I'll do is just move that a bit and then we're okay. But, see, if it drops any further, if this

		middle line starts coming down into the bottom, that's when I've got to slow down the pump speed and then that'll open it up again" • Alice: Last night within a few seconds of being on it was up in the 400, and I couldn't – and it was only when I glanced around I realized I had left the clamp on to me • Jim: looks at pressure graph and steadiness of lines indicates good fistula control to him: "But you can see how since we had that thing, the pressure is… there's the venous and see how linear they are? And that is good fistula control"
10	Alarm lights helping to assess problematicity of problem	• Felix: 47:76: green, amber, red helping to assess state • Abi: colours indicate severity of problem. Machine tells you what you need to do. 58:27.
11	Having everything visible on machine's interface (M5)	• Jim: 50:6. Likes this, instead of having to go up and down as is case with M3.

E.16 Coordination of Resources

Table E.16: Interaction strategies and issues related to coordination of resources

	Strategy/Issue	Example(s)
1.	Machine coordinates resources and attempts to tell the patient that there is a problem, but does not really guide the user on the course of action – tells system state only, and not goal at that point	• Jim: "IV: But the message that it gives is…Jim: That low conductivity…it doesn't tell you what to do. Well, in theory, if you've got low conductivity, the bag's run out and you go and change the bag. That's what used to happen in hospital." • Jim: Referring to lower ven alarm: "IV So, it could be a number of things? TO Yes, that's why you have to work your way through it all…and the way I do it is I start at the top here and I work my way down, every line, right through the machine, bit by bit, until I find out why it's doing it. If it's still doing it after that, then it's something to do with my arm and I haven't got any control over that…" • Ivan: understands what alarm messages are saying, but sometimes doesn't know why they are saying it, usually finds out what it is in the end. "Like this morning, I didn't know it was the pipe, you know, and it was alarming all the time and I didn't know why. It kept saying low water pressure, and I knew that the water pressure was okay because I've got it up here." (problem was the tube was crushed under a wheel). • Ivan: "Msgs are all the same really, doesn't really tell you anything, only low pressure or high pressure…I had one on Monday, did I? It kept alarming and I didn't know why. And in the end I undone one of the screws and released it, and it must have released something because I put it back in and it was fine. I don't know why. IV Which screw? Ivan: It's one that goes into the machine. It screws into the machine. I think what they are, they're like airlocks, you know. And this one must have got something in it because when I released it it was all right." • Terry: "Disappointed with the modern machines on this, cant detect –ve pressure here, and say have you checked you've unclamped this or left a clamp here. It will just say arterial pressure. One situation, could be a number of things that cause it. Arterial pressure, could be line, needling problem, something else, machine will just say what it can't achieve. Manuals will say have you checked this, etc...but if patient is on machine, he's not gonna get the manual sit there and read it… Would be better if machine could say to you these are the possibilities, or even cut it in half, and try and work it out closer to the mark"

2.	Machine giving suggestions for cause of an alarm and patient following these to troubleshoot	• Jim: "when the alarm comes up, it has a question mark. When you press the question mark, it gives you a list of options of what to do. Like the classic one is when you're doing a reinfusion, which is at the end, it pushes saline through the system to push all the blood in the lines back into you. What I often do is forget to release the clamp, right? So, it comes up, with an alarm saying so and so and so and so and then you press a question mark and it gives you the options of what might be wrong. It says… you know, it says that the pump could be stopped or this could be… check this, check that, check that… • Eva: 67:7: in normal situations, follows suggestions of machine and refers to them • Abi: fact that machine says what is the problem and gives suggestion gives patient half a chance to solve the problem, whereas with M2 had no choice but to call nurse/tech and read code to them. • Beth: machine's suggestions helped him solve some problems. E.g forgot to put line in clamp, machine alarmed and told him exactly that, and he fixed it. 62:4.
3.	Machine giving suggestions for cause of an alarm but not pointing exact problem or location of problem (patient has to go through the circuit to locate problem)	• Erica: machine gives options what could be wrong, when patient presses question mark. Closed clamp is one of them, but doesn't say which one, patient does a run down the line to see which clamp.
4.	Patient having to change parameter every time themselves (unnecessary repeated coord of resources)	• Garry: has to change dialysate to be processed to 26 from 24 every time. initially was 24 for 6 days, then assessed as maybe over-dialysing, changed to 26 for 5 days • Adam: Sodium on machine, 13.9, is not his, so he changes it every time to 13.8, part of his routine "the same way I always have to do it". • Gina: changes sodium every time • Carl: also has to change sodium every time
5.	When patients have to coordinate resources themselves, there is a risk of them forgetting to do a particular step or not knowing that a particular step has to be done.	• On a few occasions, Adam forgot to inject the anticoagulant and blood clotted in the dialysis line. He had to scrap the lines and start from scratch. • Gina used to forget to change the sodium setting when entering the parameters for a session, until she stuck a reminder on the machine's interface. • Fiona: She used to forget to remove clamp from unneeded line part (part not used) before throwing line to bin, and ended up throwing many clamps in bin. Now she ties the line instead of using clamp. • Nelly: biggest prob is remembering sequence of lining and priming, tend to forget little things, different things all the time • Alex: forgets some steps, but then realizes it: I mean it seems overwhelmingly at first, but you know after two or three months it's getting easier after two years it's second nature. I mean I could do it in my sleep, and

		quite often do. You know I'm half asleep when I'm doing it, but you don't forget anything. I sometimes do, and then realize I've forgotten that and do it there and then. And it usually doesn't bother the machine. • Garry: "You know, a couple of times I've missed a step and it hasn't worked, and you've got to be quite methodical about… you know, there's not a lot of give in this, you have to follow things exactly. But that's the same as most medical things I think, there's no short cuts" • Bea: 43:64: forgetting to reconnect water to machine after disinfecting water pipe (then machine alarming when she starts disinfection) • Jim: "IV And then you check these things…RI Yes, we know what it is: it's always me leaving a clamp closed." • Bea: 43:54: "Something we do that the hospital, me and the other girls and the daughters that were training with their mum, we forgot to put these on, clip on, leaving it open. Blood's pumping out. 29[Unclear]. No, no; stop, stop. There was blood going all over the floor." • Ivan: had a few mishaps, left a few ports open and got blood all over the place. Need to remember to close all clips before coming off, otherwise you get blood everywhere. "They... most of these pipes have got outlets for other things that are not used... So they've got clips on them all, so I clip them off because I made a mistake earlier where I left one open and it came... the blood came through. So I've got to make sure I clip them all off." • Neal: need to remember to clamp off unused heparin section, otherwise blood may come out. Happened in unit. Apparently some picture helps them with that? 64:8.
6.	Interface design helping patient remember to do a step when coordinating resources themselves	• Carl, who also has to change the sodium setting, says that the fact that the sodium setting is displayed on the same screen where he has to input the number of hours helps him remember to change it; the design of the machine's interface in this case indirectly helps the user to correctly coordinate resources.
7.	According to Nancy, the representation on the machine's interface that patients are most interested in is the time left for the session (a representation of the *state* resource).	• On M1, this is represented on a progress bar and in large print, on a screensaver that appears during treatment. E.g. according to Carl, Bob likes having the machine very close to him because he likes to see how much time is left. • Jim: IMG_1415. Shows resource rep patients interested in, how much time left!
8.	Coordination of resources done by the machine in some phases of the treatment can be perceived as unnecessary or even annoying	• While Ivan is coming off, he presses a button to start the termination procedure (to empty the bicart) and then starts taking his needles out. While he is holding the needles and his

		wound, the machine keeps pinging to go over to the next test: "But it keeps pinging saying, look, we've got to go over to the next test now. And that annoys me. I know what I've got to do next, but I can't do anything because I'm attending to my arm... And it's a machine for people who are in hospital, obviously, so." • Ivan: Gets on his nerves when machine keeps pinging when it's ready and he's having breakfast • Bea: 43:32 when abroad, has to have water removed because that's how machine works: "But in the modern machines now, in the new machines, when I go on holiday, I say to them, please don't take any fluid off. And they say, oh, we have to take some off and give it back to you and they do it a different way. But I don't like that because I can feel it coming off and I can feel getting lightheaded. Although it's only… I think 00:38:04 it's about 500 or something, but because they take it off first and then give it to you in saline after to balance it out, because 14 that's how their machines work… They're fantastic machines, but they're no good for me because the machine won't work unless the fluid's coming off." • Lower sensitivity of older machine preferred: Felix: " Iíve spoken to the nurses about this particular machine and some of them reckon itís better than the new ones, because the new ones are very, very sensitive. The slightest thing, the slightest off and theyíre alarming or stopping. This is a bit rugged, this particular machine. It takes a bit of abuse, if you like, and it carries on going and doing the job. And itís doing 01:03:14 the job for me, thatís the main thing, more than anything. Thatís the main thing." 47:58.
9.	Unnecessary representations of resources on machine	• Ted: 57:5: thinks interface of M5 could be simpler, too much info on it, coz they're not qualified nurses. Also 57:11: In terms of interaction, theyíre maybe too complicated for the home patients, too much information they donít actually need to know. Discovered a few of them will play, press all sorts of screens, what does this do. It ís something they wouldnít ordinarily do. But thatís their own choice. Not really creating any problems, just playing there, but doesnít need to be there. • Neal: only required icons should be on screen, have less things on screen. They try to do that and tailor icons that are on screen for patients. 64:24.
10.	Some representations on the machine's interface help the patient to understand the current *state* of the system (so they can decide on the next course of action or proceed)	• Adam, on dealing with arterial/venous pressure alarms: "The pressure gauge on the screen shows numbers go up, and then when it goes off, goes down to zero. Seeing this, you know it's the pressure. Sometimes even when the needle is in the right place and you haven't

		moved, it alarms, because it touches walls of the vein, then you check on screen if the alarm is arterial pressure [which would confirm that this is the case]". • Gina: when the machine is ready, the hours come out, and she knows from this that she can start. The display of the hours on the screen show that the goal of preparing the machine has been completed. "The hours will come out here, then I'm ready to start. That, together with the green light, the green light must show." • Alice: it gives you advisories about every half an hour, when it's doing complete system checks, it gives you the code that lasts 3 or 4 mins to tell you it's doing it…Machine flashes all these numbers when it's doing it's little checks…Once preliminary checks done and you can go ahead, it shows 2 yellow lines here…After priming, alarms twice to let you know, and brings up letters of the alphabet…When done, it change screens, it'll all come up in zeroes, time zero, dialysate zero, pump keeps going but it just pings every minute or so
11.	Resources represented by other components of TS helping patient understand current system state	• Ivan: when there was water pressure alarm (due to pipe crushed by wheel), glanced at water pressure gauge to know whether the water is coming correctly to the water unit. Gauge has a dial showing pressure, and also a dial showing target pressure • Adam: RO unit alarms only when water pressure drops, no other situation, he coordinates this resource himself to know that the problem must be the water pressure
12.	According to Ted, the fact that the machine gives an error code that the patient will note and communicate to the technician makes the patient feel that they are participating actively in the troubleshooting, rather than just saying "my machine's gone wrong".	• Anecdote from Ted. "Home patients have decided to take some control, and so they are happy to do as much as they can".
13.	Cause of problem outside scope of what patient and machine can detect	• Jim: and the way I do it is I start at the top here and I work my way down, every line, right through the machine, bit by bit, until I find out why it's doing it. If it's still doing it after that, then it's something to do with my arm and I haven't got any control over that. If it's inside that vein, then that's out of my league…" • Bea: when there was blockage in the line inside her, machine kept alarming, next day same thing in hospital, then staff thought maybe line inside is blocked.
14.	Incorrect coordination of resources by machine	• Kevin: dodgy sensors leading to batch failure (when prob batch is good) causes problems, 7 hrs preparation, then 2.5 hrs drain, then 7hrs prepare again: 54:33. 3 chances to pass conductivity test, but 9 out of 10, if failed first time, will not pass. This caused him to go 3

		days without dialysis once. • Fiona: Other incident, the machine kept alarming blood leak but there was no blood leak. Technician came and fixed it, but didn't explain what was wrong coz she didn't ask. • Carl: When mum tried to start disinfect, machine wouldn't go in disinfect mode, kept getting msg bloodline connected to SN-port. Turns on machine, goes to disinfectant, cleaning, yellow (light?) comes up with that message. Played around with it for 20 mins, then somehow got it working. Phoned techs, who explained SN was single needle port, where you twist the lines in, and suggested might be a lining problem. Then he realized couldn't be, as at that point, line isn't even there yet, still disinfect stage. Same thing next dialysis session 2 days later. Played around with it, then started working. Just cleaned everything, doors, needle ports, play with coupling, pull it, shut it, eventually stops. Hasn't happened on wards, unit contacted manufacturer and its something to do with the sensor. The door that you open has sensors in it, that's what he plays with: get a bit of Swipe, clean it, close it, open it, close it, you know, until something happens, yes. (at time of interview they hadn't figured out what problem was) • Ivan: while he was troubleshooting a problem, due to which he could not start dialysis, at one point I observed this: He clicks on one of the touchscreen buttons and gets the message: Dialyser coupling is detached. "Ah! Why didn't you say that before!" And he tries to fix dialyser coupling. Problem still not fixed…(problem was the dialyser tube was crushed under a wheel. so technically the coupling was attached to the dialyser, but the machine reports the problem as the coupling being detached, because presumably that's what it can sense it as).
15.	Patient overlooking resource coordination done by machine (involuntarily or voluntarily)	• Anecdote from Ted: Patient skipping step then getting soaked in water when changing filter: Ted: 57:16 • Terry: patients taught how to override alarms during training, and just try to override everything. Copycat, override without understanding cause of alarm • Observation of Nelly: on M4 and M5, patients tend to press mute alarm and try to restart pump, without reading message on screen, to see if that works • Ivan: "It won't alarm now. Well, it might do, and if it does I'll just kill it" • Nelly: on M5, teaches patients to do disinfection, t-test, and then line. But some patients don't always do it, they start lining before. One of the reasons for teaching it this way: the machine visually shows steps for lining, one step at a time (but if patient does

		lining before, just shows all steps as completed when time for lining comes) • Eva: 67:6: on couple of occasions, skipped procedures in haste of reacting to problem (specially when patient not well), e.g. when giving bolus: “we might have just 00:06:01 jumped one or two procedures, ie not done it exactly in the sequence that the machine wanted us to do it in, and that created a bit of a problem because then what it starts doing, it’s telling you that there is some sort of an error…” • Tom: common probs: putting line sets on too soon, not waiting for machine to complete a process before they do something. Then machine alarms, as it is running of processes, and alarms if taken out of its process. Could be patient rushing through it, or forgot something in procedure of coming on or off 66:4. • Eva: 67:6. Another time he might have skipped something was when they had conductivity alarm. Home nurse was here, and he couldn’t solve it either. Had to lose blood.
16.	Patient confident in full-proofness of machine from a safety perspective	• Cindy: “if you don’t do everything in the set order, the machine will tell you. It is full-proof and you virtually can’t make a mistake with it.” • Ivan: “you can’t really go wrong with this, and it won’t let you go on unless it’s right.” • After Carl presses the “Min UF” button on the machine, which suspends fluid removal to help re-stabilise the patient’s blood pressure after it has dropped, the machine beeps every 10 mins as a reminder that it is in this mode. He reads this as “have you taken any other action?” because the machine cannot be in that mode continuously, and he may have to do something else to alleviate the cramps of Bob. • Kevin: “Because the machine is easy to use the instructions are simple, everything’s colour coded, if you do it wrong it alarms, basically. So, yes, it’s easy to use, easy to get on with.”…” The machine… the machine itself is, yes, it’s pretty idiot proof. I mean, you would have to consciously do something stupid to mess it up” • Cindy: feels very confident using the device lot of safety features built in, and if you don’t do everything in the set order, the machine will tell you. It is full-proof and you virtually can’t make a mistake with it. • Nancy: Machine wont let patient do anything that’s unsafe, e.g Ivan put in disinfection mode that was just rinse, but machine said disinfection required • Carl: finds it really positive that the machine bleeps if you do anything wrong, that it warns and doesn’t go any further. Machine very sensitive, if you bend it too much or blood not

		flowing properly, it goes off… If you forget to clamp something or need to, machine warns you, won't go ahead until you do • Adam: Air bubble alarm: it says micro-bubbles, so you know you've got air here, you open cover, hit line, air goes up, reset alarm and it will start again • Alice: "Very sensitive, if you connect yourself up with air in lines it will just alarm non-stop until you cleared them"…"it's very clever in that, if it misses the arterial air and it goes all the way to the venous chamber rather than give it back to you, which obviously isn't a good thing, it'll alarm and it turns the pump backwards, so it pushes it back into the dialyser, so you can put a syringe on the top of the dialyser and draw the air off there." Slightest thing, sensitive machine stops the pump. • Eva: working with M5 straightforward, "It tells you every stage that you need to go through with sort of windows that come up for which you have to... it's a touch screen thing so you basically confirm that you've done what it's just told you to do" 67:5. • Tom: the concentrates that the patient will use are initialized on machine by techs, and patient chooses required concentrate (if they have more than one prescribed, and want to use one that is not default). If concentrate selected on machine does not match attached concentrate, machine will alarm. 66:6. • Beth: when forgot to set pre-dilution, machine alarmed and told him. 62:7. • Gina: if she forgets to unclamp something, the machine will stop and alarm. She then finds out where. The alarm coordinates the goal of unclamping whatever needs to be unclamped.
17.	Relying on safety-consciousness of machine during interactions	• Felix: this supports his learning by making mistakes. "Have you ever made any mistake which could be potentially unsafe? 00:48:25 TO No, because it just shuts down. Once that alarm goes off and once that stops spinning, I'm not getting any dialysis. So, it just stops." • Jim: machine sets pressure guards automatically based on what that particular patient's starting pressure is, intelligent guards. he relies on this to adopt IS of changing the guards when there are alarms, knowing that machine wont let him change to something unreasonable?? • Alex: "And you know it's… well, it's safe to fall asleep anyway, because if the machine detects any problem with blood pressure, it starts hooting and wakes you up. It's very good at that" • Ted: machines are safety conscious, much more reliable than they used to be. Will put on bypass if there's problem. • Gina: adjusting TMP before alarm goes off: She moves the limits so that the orange and

		red bars do not touch, she "separates" them. Then there will be no alarm and everything is working. She doesn't know exactly what that does. But since the machine continues working after adjusting this, it doesn't stop, she assumes that it must be ok to do that. "If it's dangerous it will stop." "if it's something serious, there's nothing you can do to make the machine start". • Gina: same with a/v alarm: adjusts limits, like with TMP, if it keeps showing high, then checks needle, resets alarm and it starts
18.	Patient modifying the plan resource that the machine coordinates against to avoid alarms	• Patient widening alarm limits as default is too narrow. Carl: "IV: You mentioned you put wide limits for pressures. Is that just because…? IE Well, because the machine itself puts very narrow limits on it, right? So that if you make the slightest movement, depending on the sensitivity of your lines or probes in your arm, I mean you can go above the limit in an instant, which switches the machine off…the default limits are perfectly okay if you've got perfectly operating lines or probes, and you don't move or do anything to upset anything. But in my opinion they're too close in practice and I just set them a couple of notches wider and that's fine." • Many other patients do same thing, both from H1 and H3 • Eva: 67:27: changes the limits when it alarms • Tom: ok for patient to widen limits, there are limits pre-set by them and by the manufacturer that the patient can't go past, so it's safe for patient to change limits. 66:12.
19.	Machine not coordinating resource (giving neither alarm nor guidance) for something that is within it's scope	• Garry: when machine was alarming (due to expired batch problem), info not provided as to how much dialysis he had done. Ideally machine should convey this, so patient knows where he had reached in overall plan of dialysing for a certain amount of time: "I also wouldn't have got any information from the machine as to how long I did, how many litres of dialysate I'd actually done." • Ida: this should be within scope of the machine. Pressure alarm problem, but before machine has started circulation (actually it seems circulation has started, since needles are already in, and prob blood would start flowing, but has something to do with it being at the start of the process, machine hasn't picked up "something" yet), so it does not alarm (but machine is on), and no number given to look up into the book. Steps for if A=0 (before machine has properly started dialysis). Follow these steps, alarm no 25 (but not displayed on machine yet). Requires them to reset the pressure pod – unscrew it and then screw it again. • Kevin: when machine stops flow because of expired batch, doesn't say how much dialysis was done. Should tell this, so patient knows

		how much was left. • Ida: 49:23: he forgot to unclamp something during washback, it went into a "spin" and machine kept alarming. They didn't know what to do, tried a few things and eventually lost the circuit of blood. Machine's lights for buttons were off, so seems this contributed to them not knowing what to do to deal with the problem? (seems normally lights are on to indicate buttons to be pressed?) • David: should have Presets on technology, to avoid removing too much fluid, e.g. patient taking off 5L and dying (anecdote of a H4 home patient) + see also 60:11.
20.	Resource coordination that should be within the scope of the TS (considering other parts of TS, not just machine)	• Erica: machine prompting when filter needs to be changed, but centurion does not say when disinfection should be done, need to remember by marking on calendar. 45:16 • Kevin: problem with coordination: pureflow batch expired, and machine simply stopped. Wouldn't let him come off, so he would have lost whole circuit of blood, had he not used the trick mentioned next
21.	Patient using trick to compensate for inadequate resource coordination by machine	• Kevin: when machine stopped because pureflow stopped supplying dialysate due to expired batch, and would not let him washback, he tricked machine by connecting syringe with saline to it, making it think flow had resumed (pureflow stopped flow, but fluid flowed from syringe, so machine thought fluid was flowing again), and then he was able to come off the machine and save his blood
22.	Carer double-checking if machine is coordinating resources correctly	• Carl: Sometimes deliberately clamps some of the lines to see if machine alarms, to ensure alarms are working, as he is apprehensive of delaying dialysis of dad
23.	Difficulty for carer to assess state of patient with blood pressure monitor	• Carl: Bp monitors giving different readings a few mins later, e.g carer saw bp was low, under 120, and thought he should give saline, but patient raised head few mins later and bp was fine then • Abi: integrated blood pressure monitor giving strange readings, so using her own at the moment. 58:13,12.
24.	Having integrated resource coordination for different components of TS	• Carl: Used to be problem with RO power switch, with the chip, wouldn't work sometimes, would stay on standby mode. But if he switched it off from mains and back on, then it would kick. Now they fixed it so that when machine is switched on, RO switches on too. • Alex: installed connection between machine and RO, so that when machine comes on in the morning (through programmed timer), RO comes on too.
25.	Patient having different possible plans for their treatment, not reflected in machine's plan	• Adam: He uses two different concentrates. When using the one that is not programmed, machine alarms, couple of resets and it doesn't alarm anymore

26.	In some situations, e.g. going for operation, patient has to coordinate a modified plan resource	• Felix: he would have to know himself when he needs to use saline and not tinzaparin, on eve of operation: "Like, say, if I'm going for an operation tomorrow, I wouldn't have used tinzaparin today. They would have told me not to use it. I would have used saline."
27.	Emergency button – patient letting machine know of patient's problematic state, so machine can react accordingly	• Ivan: incident where he almost passed out, "was under the weather", stage where you don't know what you're doing, difficult to remember what he did…but he pressed minimum UF button, felt better, and when wife came up he asked her to turn on the saline. Soon brings you round. • Other patients used the button too
28.	Machine giving patient chance to rectify problem before stopping flow (letting user intervene before proceeding with plan, which would stop their dialysis)	• Alice: it always gives the yellow (advisory) before the red (actual alarm and pump stopped) so you have a chance to just do a quick circuit check and see if you've got a clamp on or a line kinked before it gives you a red… Gets warnings when maybe pressure limits are coming, then it'll be something daft like you've got the line slightly kinked or daft things.
29.	Need for override mode	• Eva: 67:10: "Where I think it's more of an issue is when you're dealing with an emergency situation and it's probably maybe something that you feel more if, as a carer, 00:15:45 you're related to the person that you're treating, because it's always going to be a little bit different to what a nurse would be doing. They'd be a bit more detached and in a more clinical environment. So, you know, if it's your mum or somebody like that who is feeling sick, you tend to immediately just want to...00:16:01 CA And then he worries obviously. I think it's a worrying thing. JA So sometimes the last thing you want to see is another message come up that's asking you to read something when maybe the person is passing out." Should probably have a button for panic mode, override everything and just let carer administer bolus?
30.	New software/modules for machine that increase the scope of resource coordination done by machine	• Neal: software on machine can now tell if patient is dialysing well during dialysis itself, can tell if there is recirculation of the blood (same blood dialysed again). In unit, not yet at home. 64:18. • Neal: machine can monitor patient's blood pressure and prompt patient about it or alarm if limit reached. 64:19. • Tom: Fres has red sensor (detects if blood on arm and stops pump immediately) and needle dislodgement sensor (they don't have it yet at H4) • David: new sensor for detecting density of blood when it passes in a chamber in machine, cutoffs to prevent decrease in blood pressure • David: new sensor on arm to detect blood on arm (red light thing), other sensor to detect moisture on arm (could be blood)

		• David: new part/module for administering iron. See also 60:14.
31.	Restricting extent to which patient can change plan, as safety precaution	• Patients can change some params, but some not: Ted: 57:14. Due to safety

E.17 Representation-Goal Parity

Table E.17: Interaction strategies and issues related to representation-goal parity

	Strategy/Issue	Example(s)
1.	When dealing with arterial/venous pressure alarms, some patients rely on external representations that indicate exactly what the current *state* of the system is compared to the target *state* (*goal*).	• When a pressure alarm seems to be due to the position of the needle going into his arm, Adam adjusts the position of the needle while looking at the vertical pressure meter on the machine's interface, which goes up or down real-time, until the pressure gets in the normal area. (picture img_0884 shows pressure meters and limits) • On M2, the current pressure is indicated by an orange horizontal bar, while the upper and lower limits are indicated by red horizontal bars above and below the orange bar respectively. When the orange bar overlaps with either the upper or lower red bar, a pressure alarm is triggered. The first thing that Fiona tries when dealing with the alarm is turning a knob on the interface to move the overlapping red bar away from the orange bar, effectively re-adjusting the corresponding pressure limit, until the two bars no longer overlap. Fiona: "if that, this red button and this orange one, meet up, it will start alarming, that means there's a lot of pressure on the venous, and normally you just press that, and then, that, like, and then just change it up. Lower it or make it bigger, or whatever depending on where it's alarming." One bar for venous pressure (middle) and one bar above and one below (lower and upper limits). • Same as above for Gina • Garry: "IV So, after you've jiggled the needle, how do you know then that it's correct? IE you see the number's coming down…literally, as you're moving the needle, you can see it fluctuating. And it is quite sensitive."
2.	Referring to pressure graph/bar, which has good representation-goal parity, to know current state and anticipate problems	• Jim: IMG_1395. Shows pressure guards (boxes) and current pressure (green line). Also 47:44 • Felix: "So, then I just keep an eye on this all the time. If this drops or that goes up, then I'll have to spread the alarm....See, that's dropping a bit now, on to this marker? What I'll do now is, I'll bring that down. See how it's… if you leave it too long, it's going to alarm. What I'll do is just move that a bit and then we're okay. But, see, if it drops any further, if this middle line starts coming down into the bottom, that's when I've got to slow down the pump speed and then that'll open it up again"
3.	Good rep-goal parity when increasing pressure alarm limits	• Felix: "What I'm doing now, you see these dark blue lines, well, what I do is I bring that

		down to there and across to there and I just space them a bit, one, two, see how they opened up? Now I go across to that one, one, two, just to get it away, because if this touches this, the alarm will go off, you see? Well, they tend to jump up and down. Now, that's perfect at the moment, so I confirm that I'm happy with that and then I just leave it."
4.	Good rep-goal parity of gauge of water unit	• Felix: 47:71. When there is water pressure problem, water pressure gauge lets patient know at a glance if it is a problem with lack of water coming in
5.	Poor representation-goal parity provided by machine for some problems. In some cases, even though the machine coordinates resources and attempts to tell the patient what the problem is, the machine's message is not really understandable by the user	• When machine says conductivity issue: it is a representation of a system state (a problematic one). But this rep is better when it says water shortage, instead of just conductivity, as in 47:72, and see Erica: 45:24 • Once Adam struggled with a particular alarm he never got before. After spending some time analysing the setup of the machine, he realized that the sodium bicarbonate connecter got dislodged out of the canister. Though the solution was simple, that is just putting the connector back into the canister, the message displayed by the machine did not really point towards it. E.g, displacement of bicarbonate line due to crossing with arterial line: alarm comes up, doesn't understand message, which doesn't say check acid. • Adam finds messages of the device, terminology, not really understandable, specially alarms. Msgs contain abbreviations, codes. Sometimes msg gives 90% info of what's wrong, sometimes less than 50%, sometimes doesn't understand at all. When water pressure drops, alarm says concentrate "conductivity low" or something, and just need to press couple of buttons, reset alarm on RO and on machine • Jim: 50:36 • Felix: "I mean, we have a disinfectant bottle on the back. Well, of course, they last about six weeks. When it come up, it was telling me but it was spelt C L I G or something, which meant it had run out, but I didn't know. And I'm pressing this and pressing that and it wouldn't do it and the alarm was going mad. But it had run out of disinfectant, but of course, it was on the back of the machine. So, I rang up the technicians and he said, what does it say? And I read what it said on the machine and then he said, yes, your disinfectant's empty at the back." • Jim: "IV: So, you were saying that when you didn't clip this thing, the alarm gives a message? Jim: Yes, lower ven alarm. But I didn't know what the lower ven arm was. I know this is the lower ven, it's your venous.

		The ven, it stands for venous, I know that. But I'm looking at the needle, aren't I? And this door was shut and we just couldn't suss it. So, you do the whole thing, like, you just go and start at the top and you work through all the tubes, you look at everything, open the door, and there the bloody thing was sitting out. I pushed it back in and it was perfect." • Fiona: Understands pretty much most of the language of the device, but does not understand every part of the device, not every language of it. Sometimes she has to phone the nurse and ask what it means. "yeah some of the messages are a bit, the language, they could change the way it's written. Coz sometimes it takes me quite a while to understand what it means or what it's trying to tell me to do." • Carl: Incident where machine kept alarming, turned alarm off, it restarted again and then after few seconds alarmed again. Msg said dialyser something. He looked at dilayser (artificial kidney) but couldn't see anything abnormal. Called engineer who couldn't work out, asked him to reline. So re-disinfected and re-lined (patient waited 45 mins again). During disinfect, he looked at back of machine and saw water leaking at filter. • Ivan: Had one incident in beginning where it kept alarming and he couldn't fathom out why, in the end scrapped whole lot and put new lot and it worked (that's what H1 told him to do, couldn't tell him why it was alarming) • Ivan: it doesn't actually tell you what the problem is, e.g. to him that's not a drainage pipe (inlet and outlet). Drain line was under wheel. • Cindy: Sometimes machine just tells you what is wrong and you can put it right straightaway (e.g. either venous pressure or arterial pressure is wrong), but sometimes it gives a code you cannot understand, then you phone the technicians • Carl: after dialysis, a probe needs to go back into the machine. Once he didn't click it properly, and machine wouldn't disinfect. He couldn't understand message displayed. Called technician who said it was probably the probe. • Eva: 67:10: terminology can be problematic: "sometimes what is still a bit difficult is that the terminology that they use. Yes, they talk about... how do you call that valve which we normally forget to close, the venous...? JA Yes, the online...CA The port... yes, so unless you know what it is..."
6.	On M2, flashing spanner sign indicates that the technician should be called for	• Gina: when there's a problem with the machine, the spanner sign gets lighted red,

	an alarm (good rep-goal parity)	and when she presses it, it asks her to call the technician (doesn't ask her, but spanner sign hints at that) • Fiona: when spanner thing keeps flashing, that's how she knows there's something wrong with the machine

E.18 Mediating Artefacts

Table E.18: Interaction strategies and issues related to mediating artefacts

	Strategy/Issue	Example(s)
1.	The dialysis chart is also used by some patients to help them keep track of when they did some things or of problems they encountered.	• Adam records things he observes or he does in the chart, e.g. "strange post-weight", or "changed BPS [blood pump speed] to 300 since TMP [trans-membrane pressure] alarmed a lot" • Cindy puts a note in the dialysis chart when she does the special disinfection programme (CCART clean) on the machine, to help her know when she needs to do it again. She also notes down when she does the monthly bloods. • Garry: 48:41. Records problems/alarms on sheet, but more for purpose of taking them with him to hospital, and unit staff will take a look at last month's worth of sheets • Jill: In her dialysis chart, she records when she has taken Venofer, which she needs to take once a month, to know when next to take. She records when she has taken epos, of which she has to take 4000 units every 5 days. Otherwise she would forget when she took these.
2.	Some participants record alarm codes and solutions given by the technician in their dialysis chart or a separate diary, to refer back to these solutions in the future when the same problem is faced again.	• Jill records alarm codes in her diary, together with comments and problems, and she looks back at them. • Example of an entry of an error code and its solution in Jill's dialysis chart. The error code is "088005", and the solution is "red horizontal light → click, 4-5 times". • Cindy keeps a troubleshooting diary, recording alarms and actions taken to remedy, and then repeats same actions next time alarm comes up…in some cases the same actions do not work, or work after several attempts. See pictures of diary. • Gina: writes down the solutions for the alarm codes that are handled by the technician in her diary. Next time if the same code appears, she refers to the diary and she knows what to do. She has been coping like this, and rarely calls them. E.g: "COFFB088021: this is one of the codes, switch off and restart, usually corrects itself, if not, call the technician, yes. This is another code. Clean the venous clamp area with damp cloth, maybe it has… that is first [unclear] then this is another code, this one. Check the blue and red connections in front of machine to make sure it's well connected." When a code different from the ones she has written down comes up, she writes it down. Like a COFF088094, if it happens he said it could be air in bicarb tube... So, you check bicarb peak tube to make sure it clings to the

		hand. That is if this code appears, it means that I didn't connect this properly"…"saving time, because if you call them you have to wait. Because they don't have their master book there. Sometimes they tell me they are going to their car to get the master book and then you have to wait for them and then they ring back. They look for it and they ring back. So, it's a waste of time for me. So, if they tell me I write it own and next time I don't need to call them and I carry on with it."
3.	Another way of getting solutions for alarms is consulting the machine's manual.	• The first time Adam got a low water pressure alarm, the machine asked him to check the concentrate, but he couldn't see anything wrong with it. He consulted the book, which said he just had to start the conductivity test again. Checked book in the beginning for first few alarms. If something internal, check alarm code, refer to book, book says contact technician. • Ted: patients tell him they do refer to manual, and they very rarely call him again for the same problem, as they remember in the future • Bea: 43:19,43:22 • Garry: 48:23,24,25,26,27 • Ida: 49:32,37. • Kevin: 54:14 • Alice: Reference alarm code on screen to manual, alarm shooting, to know what problem is, always gives you answer sort of thing…Once in a while you get one you don't remember, get out book and you go alright…Manual tells you what alarms are, always gives you the answer sort of thing, it's very clever…"The manuals are fantastic. Literally you cannot go wrong with them you know. They're so straightforward. So I think maybe if you did have a problem with these, it would be more operator trouble than the actual machine itself." • Ivan: Referred to instructions manual for cleaning, tell you how to turn the things off because there's a sequence of turning it off otherwise it won't work properly. Now he knows it by heart. It wasn't really self explanatory, but was useful. • Cindy: Doesn't understand most of the machine's manual, but when had to change filter, read it, sounded easy, and just did it herself. Manual tells you what machine would tell you to do in each stage.
4.	Patients also use other artefacts that act as plan resources.	• To allow his mum to turn on the machine and start the disinfection process, Carl put a set of stickers on the machine's touchscreen. These stickers, in the shape of red dots, indicate to his mum which buttons she needs to press: 1) press "On"; 2) press "Function"; 3) press "Disinfect"; and 4) press "Prim-ven" [Prime Venous]

5.	Mediating artefact serving as a reminder	• Gina put a note on her machine's interface to remind her to set the sodium setting to 138 every time she programs a treatment session, ("REM TO SET SODIUM TO 138")
6.	While some patients find using a manual helpful, others do not, or manual not a practically viable option	• Fiona was given a booklet in the beginning to guide her in the steps required to connect herself to the machine and to help her deal with alarms. For some time, she tried using it to solve alarms herself, but she found it "not straightforward" and she couldn't fully understand it, so she ended up just calling a technician when she had a problem. • Anecdote from Nancy. according to the nurse, it is easier to use the manual when the patient has a helper: "one reads and one does". Patient who is completely on their own may be less inclined to use the manual. • Anecdote from Terry. according to the home nurse and the technicians, patients want someone to tell them what to do, rather than looking in a book, and therefore the first thing some of them do when there is a problem is phone for help. • According to Terry, some problems can be caused by a number of things, and the machine will just say what it cannot achieve. the manual offers help by listing the things that the patient should check as the cause of the problem, but if a patient is already on the machine, the patient is unlikely to "get the manual, sit there, and read it" (suggesting that a patient who is already connected to the machine might be in a state of mind in which getting the manual and reading it would not seem a natural thing to do).
7.	Instructions for doing specific tricky things	• Alex put instructions for tricky procedures/things on wall. IMG_1303.JPG. instructions for uncommon procs (saline flush and re-circulation). IMG_1316.JPG. Instructions on wall for taking blood samples. • Carl: Nurse wrote down instructions for him for dealing with bp drop, how to dispense saline
8.	Referring to topology diagram on machine when fault finding or lining	• Jim: 50:42 • Eva: 67:9: referred to interactive diagram in beginning, shows where you have to hook line next. • Eva: 67:9: Still good to have visual prompt now, through diagram. Once she connected in wrong place (on dialyser), and machine apparently told her it was wrong, arterial wrongly connected or something. 67:12: not sure that machine alarmed in incident where she wrongly connected to dialyser, thinks he picked up on it before, not sure machine would pick up on it • Tom: machine helping patient with lining, through diagram, which also tells tehm if something is wrong. 66:13.

9.	Hospital providing A to B diagrams showing step by step dialysis setup and treatment	• Bea: 43:65 (also there is a pic of it) • Referring to book and topology diagram in early stages: Felix: 47:53 (need to double check this, not sure which book is meant and which topology diagram)
10.	Referring to training notes/booklets when forgotten procedures	• Bea: "Sometimes, if I've been away 00:19:22 for a week, you think now what have I got to do next? So, I mean, I collected these on the course and then I put them in, so I know…" • Felix: 47:19. For proc for taking blood sample, done once a month, so used to forget in beginning and looked at book
11.	Using alarm shortlists to facilitate troubleshooting	• Garry: IMG_1366. Chart showing solutions for different alarm codes. 48:13,44. Don't have to open book every time alarm goes off. Put it on wall, have pic of it. • Ida: 49:68: started to prepare her own shortlist too, in the front of her folder • Alice: machine gives an error code with the alarm, and you reference that to the manual. Company that does training give you like a flash card with the immediate ones you're more likely to get. So don't have to have the whole book to hand all of the time.
12.	Using quick guide	• Beth: 62:9. finds quick guide for getting on and off very good for him.
13.	Using calendar for planning treatment days and different treatment activities (drugs, disinfection)	• Carl: Remembers when to give injections (iron and aranesp) to dad by marking on a calendar, and also on dialysis chart so when he's about to dialyse him it's there. On calendar puts when has to be given next, and calendar is on table there. On chart puts note iron given, aranesp given. Has to alternate between iron and epo, that's also marked on calendar • Felix: IMG_1363. Calendar for treatment. 47:22, 47:34 • Bea: IMG_1331. Calendar for planning treatment, 43:30, 43:48, 43:50 • Garry: IMG_1375-76.calendar for treatment. 48:47 • Ida: IMG_1389. Calendar for treatment. 49:45. • Jim: IMG_1412,13,14. Own calendar for managing treatment, includes dialysis days, drugs, blood sampling, disinfections, other comments about treatment and problems with machine, delivery, water sample. color coded. 50:14,29. • Erica: 45:16,45:18. Interesting strategy of relying on looking at calendar for date when filling up dialysis sheet to see other things that have been listed as to be done on that day
14.	Modifying default artefact to suit patient's needs	• Jim: IMG_1409. Adapted dialysis chart (removed line for first hour of measurements, only 2nd hr there). 50:33. • Abi: designed her own dialysis chart as she doesn't need some parts which are on hospital's chart, which are needed by nurses.

		It has everything the clinicians need. 58:45,66,67.
15.	Augmenting default artefact to make it easier for patient to use, adding more detail to default instructions based on experiences, or adding missing instructions	• Ida: IMG_1383. Added own color coding on default notes to facilitate understanding. • Jim: IMG_1406. Added more detail on his own to instructions for dealing with hypo (how to give the saline). Also 50:27. • Ida: IMG_1383. 49:33. added clarifications for procedures (that is press Treatment if it is a caution, i.e. no air detected, instead of muting and stopping it) • Bea: IMG_1339,40,41. additions to default instructions based on understanding. 43:45,43:53 • Ida: Adding missing instructions to troubleshooting manual (for situation where machine does not provide alarm number to be referred) Ida: 49:17: added notes on how to deal with situation when A=0 (normally alarm 25) but no alarm or alarm number because machine hasn't started circulation
16.	Creating own notes for some procedures, based on own understanding (for future reference but also for them to better understand)	• Ida: IMG_1380,81. Own notes for procs, e.g disconnection and coming off early. 49:50. Still does refer to these notes: 49:52 • Ida: 49:50. Needs to make notes to understand, needs things written down. • Jim: 50:26. Also made own notes while being taught procs in unit. • Creating new artefact, instructions for something not encountered during training (and possibly not mentioned in default artefacts): Bea: IMG_1339,40,41. Custom instructions (to come off mid flow). 43:45,53. incident, in which she had to take herself off, with instructions from nurse on phone, after which she made the notes for coming off mid-flow. Nurse forgot to tell her, to turn UF off (?), after she did that, she could proceed. So she noted that down.
17.	Technician's "master book" as mediating artefact	• Gina: if she has a problem with the machine, she calls the technician. Technician will ask her to check code, and then he will look up from the master book and tell her what to do. • Jill: Red hand alarm -> press button, tells you what error is, then phone technician and read error to him. Or sometimes it has a number, technician looks into book of codes and it tells them what's wrong with the machine. If something simple, they would tell her to try this, that, turn machine off from back, wiggle this, turn that off, press this. • Some other patients also referred to the "master book"
18.	Interface design deprecating mediating artefact	• Abi: 58:10: before had instructions on wall what to do when passing out, several things manually on M2: clamp lines, reduce pump speed, undo saline. With emergency button on m5, simplified. Just press that.

E.19 Cultural Heritage

Table E.19: Interaction strategies and issues related to cultural heritage

	Strategy/Issue	Example(s)
1.	Exposing kids to treatment	• Jim: dialysing in living room and exposing kids to treatment has a benefit: 50:18: they may get it later too, and so they will already have seen how to do it, that it can be done, etc…
2.	Generation gap in handling machine	• Abi: 58:58: a generation gap in understanding machine - she can understand different areas on interface, mum gets confused, only knows emergency button and how to increase/decrease pump speed
3.	Staff learning from patient experiences to improve experience of future patients	• Nancy: Recently added checklist for training for patient at MRDU, covering how to take themselves off to go to toilet, added safety features such as do they know what their medications are and what adverse reactions there might be, extra precautions not necessary if dialyzing on unit, extra knowedge that might come in handy, knowing right language to use to troubleshoot over phone • Nelly: added water leak detector, after incident in which patient's house got flooded. 43:63, 55:26 • Beth: 63:5: example of staff adjusting practice based on patient's experience: using bigger biobag on M5, as smaller one runs out with 5,10 mins left.
4.	Technology designer improving design and future patients benefiting from it	• Erica: says when there is a water shortage (instead of just conductivity like on other machines): 45:24. Good example of rep-goal parity • Examples of how new features in newer machines solve problems with older machine: touchscreen not requiring physical pressure like buttons of old machines? Alex who has physical problems due to other conditions, finds it hard to press buttons on his older M4 - perhaps he should have M5 • Comparison of M4 and M5 – old one doesn't give suggestions for problems, new one does • Abi: has less problems with current machine than previous one, M2, got spanner codes all the time and had to call techs to come out. 58:23. • Beth: 62:3: old Cambridge machine, had to re-use parts, complicated, now it's easier. 62:10. • Beth: 62:5: current machine telling what is wrong, with older one had to go through everything (M2). • Beth: 62:25: current machine easier than previous one (M2) • Neal: e.g. of manufacturer refining design:

		64:3: having remote control, for patients who have trouble reaching machine. • Erica: design improved over time such that lining of circuit results in less kinking. 45:21. • Examples given in Coordination of Resources analysis of new software/modules that increase scope of machine's coordination of resources
5.	Home machine 'inheriting' design feature from unit machine, that makes sense in unit but not in home	• While Ivan is coming off, he presses a button to start the termination procedure (to empty the bicart) and then starts taking his needles out. While he is holding the needles and his wound, the machine keeps pinging to go over to the next test: "But it keeps pinging saying, look, we've got to go over to the next test now. And that annoys me. I know what I've got to do next, but I can't do anything because I'm attending to my arm... And it's a machine for people who are in hospital, obviously, so."

E.20 Expert Coupling

Table E.20: Interaction strategies and issues related to expert coupling

	Strategy/Issue	Example(s)
1.	Strong level of knowledge and confidence, dialysis procedures becoming routine	• Fiona: Remembers steps because steps are in her head now, memorized, in 2nd year. • Gina: Remembering all the different steps involved (treatment params, clips): "through practice" • Abi: 58:43: doesn't feel unsafe in any way because she has had years of it. • Abi: 58:36: confident using machine as been using it for so many years, but also because machine gives you options, tells you what is wrong, can try suggestions, and phone staff and tell them what machine is saying. Instead of just having to come off as on M2. Good coord of resources by machine contributing to confidence, and patient experience. • Alex: forgets some steps, but then realizes it: "I mean it seems overwhelmingly at first, but you know after two or three months it's getting easier after two years it's second nature. I mean I could do it in my sleep, and quite often do. You know I'm half asleep when I'm doing it, but you don't forget anything. I sometimes do, and then realize I've forgotten that and do it there and then. And it usually doesn't bother the machine." • Erica: "But most of the things, after doing it as long as we have now, it is very routine. You practically do it without thinking."..."It ís just a case you get gradually quicker with it if youíre used to it. Like driving, when you start driving youíre very slow but after a few years driving, everything comes naturally and thatís the same with this. Itís a case of when youíre doing things long enough, it comes naturally, doesnít it?" 45:20,23. • Felix: "Is there anything that you find tricky or difficult to do on the machine that you think would be [overtalking]. TO Not really, not now. Itís starting to get a bit like second nature. Itís like driving a car, isnít it? You just get used to it. When you first started driving a car, you used to look at the gears, didnít you, to change gears? Everybody does. They 00:43:07 look to see where theyíre going. Now, you donít look at the gearstick, do you? Itís the same with that. You just crack on, you know what I mean? You do get very, very used to it. It is just second nature now. I donít really think about what Iím doing now. Like, when I come through that door, I just go in auto mode, you know what I mean? I do the same system 00:43:31 every day. I work out how I set it up, you know what I mean? So, itís just repetitive, isnít it? It just goes on and on and on and yes,

		no, you just crack on, you donít think about it at all. I think if you thought about it too much, youíd freeze." 47:52… Felix: "Again, you just know what youíve got to do. 01:22:08 And Iíve been doing it a while now, well over a year, so you get into a routine, youíre just on automatic pilot. You just know when itís got to be done." 47:68 • Garry: "Is there anything in particular that you find tricky, or, difficult to do with the machine? 00:40:34 IE Not really, no, I mean, because Iíve been doing it for a while, it was quite daunting to start off with, but, no, not really."48:54…" I do prefer it, but it is quite daunting learning, you know, it took me probably four or five months to not worry about it. Now, if thereís a problem I usually know what to do to sort it out, but, initially, itís quite daunting, and because the nurses train people all the 00:54:04 time, itís your only experience of doing it. Whereas with them, they do itÖ they do it weekly, so, thereís nothing that really bothered me with the training but itís just getting your head roundÖ Because, you know, Iím a chef, I cook things, and I follow recipes, and this very much the same. Thereís a recipe for setting the machine up, thereís a recipe for if 00:54:27 thereís something goes wrong, you know, and you want something good to come out of it at the end." 48:62. • Ida: knows typical alarm numbers they will get and what they mean. 49:67.
2.	Surpassing knowledge of staff	• Abi: 58:57: knowing more than nurses, as spends more time with machine • Alice knowing better than nurse who said not good dialyse too often
3.	Reaction to alarms, swift or even pre-emptive, patient coupled with environment, even though message may not be explanatory, knows what it means now. Also with time, they get fewer alarms, as they learn to couple with the environment – avoiding pressure alarms by minding arm position, building pump speed slowly, setting wide limits, etc…	• Automated ways of checking if dialysis is going well – e.g. Gina double checking pressures in beginning • Same as above for Alice and several other patients • Alice: "With me the main ones I would get would be like an air alarm, which 9 times out of ten just will settle itself. Or pressure alarm and again that will just be something like a visual check of have I got a line kinked or – I mean, last night would be sort of an example when I was bringing – I know that my venous pressure is never over hundred and eighty, and if it is, something isn't going on somewhere in the circuit. Last night within a few seconds of being on it was up in the 400, and I couldn't – and it was only when I glanced around I realized I had left the clamp on to me, so it was a case of silencing the machine, letting the pressure settle right back down, and then just starting it again. So it's sort of a visual thing, you see that number come up and you know that it's – you know, you get to know which – I think because of the training it's drilled into you, if you get a ten it's this, eleven's this, and you know, so on.

		• Fiona: machine doesn't say exactly what is wrong (it says venous pressure), but she is so coupled with it, experienced, that she reads it as forgot to connect draining tubes (and she, incorrectly, tells me that that is what machine says). Sometimes she will see it before it starts alarming, and will fix it before it happens. "like if I've forgotten to connect one of the tubes without like, first I have to prime and then forgot to connect the draining tubes into the dialyser, if I forget to connect some of the tubes it will alarm and tell me that I've forgotten to connect the tube in, or you forgot to unclip. Coz sometimes when you're priming you forget to unclip the water to go through, alarm that says no water going through. So you could unclip it so the water is released so it can go on the machine and prime." When forget to connect draining tube into dialyser, message says venous pressure. When forget to connect unclip water during priming, message says water isn't flowing.
4.	Knowing nuances of using machine	• Alice: Occasionally uses surgical clamps to undo the lines, as they tend to sort of tighten themselves once you've used them for a while, maybe the body heat of your blood going through tightens them a bit. • Alice: "I will always set my _ a couple of hours before I use it. Coz I find the longer you leave it, the more it gets to room temperature which is better as well. And I tend to find it clears the air bubbles on its own. And then once it's done it, it can just carry on and do its own thing, and you can go back to it at any stage." • Alice: found that when machine gets to a certain temperature it struggles to maintain itself and starts to alarm and things like that, so in winter she remembers to leave the on, and ensures she has 2 or 3 days of stock there. • Alice: building pressure slowly to avoid alarm: Occasionally while you're just building up to that 500 it will alarm a little, just while maybe a needle is settling and the pressures just need to – you maybe don't go straight to 500 in 5 mins, you maybe do it over ten mins instead. • Gina: Hearing normal sound of machine
5.	Modifying steps learnt	• Gina changing TMP limits in beginning so that alarms do not go off, wasn't taught that, but started doing it on her own • Lining during disinfection, done by many other patients
6.	Dialysing on weekend, without unit support	• Ivan: In the beginning they wanted to be in touch with H1 while dialyzing, but now they can do weekend. in beginning, while Ivan was learning, they wanted to be in touch with H1 while dialysis, therefore didn't do weekend. Now that he seems to have got control of it all, they will start doing on the weekend. Wants to do 4 days, and 3 days in a row makes him feel rough, it's too much. thinks he will do mon,wed,fri and sat. should be better for him.

		• Gina: dialyses on Sunday, even though unit support not available. Last year she had tinzaparin incident on Sunday, called 999. thinks they make you sign that you won't dialyse on weekend just to cover their backs. (and mentions that people dialyse in the unit on sat) she decided to do it alternate days, good for her, 4x good for her, gives her more privilege to eat what she wants (so one of the days falls on weekend, her choice) • Beth: dialyses on weekend sometimes. 62:17.
7.	Dialysing at night, or sleeping while dialysing	• Fiona: possibility due to low level of alarms: now that she hardly alarms anymore, she prefers to dialyse at night while she's going to bed, this passes the 4hrs instead of her just sitting doing nothing waiting to come off. • Gina: can sleep and listen to alarm at same time, closely coupled. If she doesn't fancy doing anything, she just closes her eyes and sees if she can sleep, but "must not sleep too deeply", opens her ears at same time to listen to any alarm. • Alex also sleeps while dialysing • Ted: anecdote: one patient learnt how to sleep properly to avoid alarms. Initially alarms would go off when he moved while sleeping • Tom: Anecdote: patient of other hospital who does nocturnal, bandages whole arm, says needle is so secure that he can pull machine with his line without needle coming off. (Risk with nocturnal is needle coming off.) nocturnal patients tend to be the most confident ones. Nocturnal is the next leap of faith for a home patient.

E.21 Temporal Layouts

Table E.21: Interaction strategies and issues related to temporal layouts

	Strategy/Issue	Example(s)
1.	Dialysis taking a lot of patient/carer's time	• Ida: ordering supplies: "when you add up the time of the pack, doing the sacks, ordering all your supplies, it's a lot more than 25 hours a week really" • Kevin: 54:3: simply doesn't have time for getting involved in stuff around the house and doing things with the family. Has girlfriend as well. It is just like he's never available. • Machine takes significant time of Adam who is self-caring, more than what he expected, and thinks it is more compared to self-caring at the unit. "I don't have so much time now like I was dialyzing at hospital. Then you had only 3 days and 4 four days a week you are free. Here I'm doing more days plus it takes longer for example. You put the machine for…disinfection, and when it finish, it actually it takes longer than at hospital." • Still having to do something dialysis-related even when not dialysing: Felix: 47:36: bleaching water/waste lines
2.	Duration of Dialysis activity unpredictable	• Can't tell how long it will be, e.g. bleeding can go on for a while, 45 mins or 1 min: Felix: 47:49
3.	Interleaving Dialysis activity with activities of HS	• Bea: starts disinf, lines while disinf, then goes to do other home things, e.g. doing bed, then comes back to dialysis • Having breakfast in meantime: Ida: 49:62 • Abi: Describes hospital experience: go on transport, reach there 2 hrs before your dialysis, what to do with this time. all patients treated the same (like conveyor belt in factory or something like that she said). One in, one out. Then you finish, go and sit on the wooden chair, wait for transport. Much better at home, you can do other things, e.g. while it is disinfecting. fit the dialysis around the things you are doing. 59:19. • Gina: disinfection takes 35 mins, if she has everything ready. During disinfection she puts the lines. Then at some point it will ask her to connect the dialysate and the bicart. Then goes to prepare her sandwich, showers, etc.. and as soon as green light appears, she starts. • Jill: Put water lever on, for the pipe that goes into the RO; put RO on; put machine on; heat disinfection. takes about 45 mins, she is having lunch downstairs during that time. • Interleaving with other activities has risk of reaching timeout: Bea: 43:17: "I've programmed it just for the two hours to go on, I've got half an hour before I actually run

		out… I don't know what happens if you… you know, if I think, oh, I'd better go and have my breakfast, or something. Once it's been primed and I've programmed it for my two hours, I have to be on it within half an hour. It still carries on priming. Yes. IV So until you start, it's going to keep priming it? IE Yes. 00:18:57 IV For 30 minutes. And then it's going to stop and so you have to start the dialysis within 30 minutes of programming it. IE Yes, yes. IV Otherwise, it's going to… IE I don't know. I've never asked." • Ivan: "do you have some ways of optimising on the time you spend with the whole dialysis process? What I usually do first thing in the morning, I usually line it out while Yvonne's having a shower and then I go in the shower when she comes out. And when I come out I have my breakfast and the machine's all ready for me to start."
4.	Optimising on time spent in Dialysis activity	• Carl: fixed (another) water leak problem himself, cut hose where there was kink and reconnected it to machine: 17:1. Did that to save time, as technician could only come later. • Adam: follows steps taught, not developed any steps, except for doing priming during disinfection. Does this to not waste any minute, feels machine takes a lot of his time. • Carl: According to Carl, Bob gets very stressed and tired with his treatment, and likes to "get it over and done with as soon as possible". Therefore, Carl tries to get Bob's treatment done in as little time as possible. When the machine has finished disinfection and is undergoing priming, he prepares the tray, measures Bob's blood pressure, blood sugar level, and temperature, so that Bob's can start treatment as soon as the machine is ready. Then, when connecting or disconnecting (during washback) Bob from the machine, Carl has to wait for the blood to go through the dialyser. Since this takes some time, Carl increases the blood pump speed from 150 ml/s to 200 ml/s, so that Bob's blood moves faster within the extracorporeal circuit, and dialysis can be started sooner (note that, during dialysis, Carl has to set the blood pump speed to what the nephrologist prescribed for Bob, to maintain Bob's cardiovascular stability). Additionally, Carl prepares for taking Bob off the machine in advance, so that Bob can be taken off the machine as soon as treatment ends, "within three, four minutes…maximum five minutes". This includes preparing the tray, preparing syringes with injections of TPA and saline, measuring Bob's blood pressure. • Carl: After disinfection, priming takes another ten 15 mins. As soon as disinfected,

		Carl calls Bob to do blood pressure, check sugar and temperature, and gets tray ready well beforehand, so that as soon machine is ready, he can start, to speed up things. • While her machine is priming the line, Gina positions herself on her bed, and lays all items she will need (e.g. dressings, blood pressure monitor) and may need (e.g. painkiller, mobile phone) around her on the bed, so that, as soon as the machine shows the green light, she can start dialysis. • Adam: Once had to change line twice, because he forgot to inject heparin and blood coagulated. Still happens, not so often, he rushes to connect, and forgets heparin. • Alice: utilising chance to fix pressure issue before actual alarm. Machine design supports this. • Ivan: planning to dialyse in less time to make more of the day • Nancy: "Yes, oh, any patient, please save me time." • Bea: lining during disinf to save time: "43:57,14. • Felix: lining during disinf to save time: "47:56 • Jim: sometimes laces during T1, would save minimal time"50:41 • Garry: found he could set params to zero to end dialysis prematurely"48:57 • Garry: taking off both needles at same time during termination instead of one after another"48:61 • Jim: in unit, asked nurse to change bicarb in beginning itself so it doesn't stop during dialysis, as M1 adds ten mins to re-calibrate "50:39 • Nelly: teaches patients to do disinfection, t-test, and then line. But patients don't always do it. Reasons for doing it this way: 1) this way machine shows steps for lining. 2) to avoid wasting line and dialyser in case t-test fails 3) to avoid getting scalded by opening port during heat disinf. if they forgot and opened wrong port. though technically can do part of lining during disinf (except for port where the hot water would come out during heat disinf) they would need to later on open the port for the priming (so risk is they forget, and open it already during heat disinf) "55:29 • Felix: changing guards to avoid alarms and pump stopping, as every time it stops it means session will be extended"47:63 • Gina: Motivation for writing down alarm codes and then handling them herself next time without the technician? Of course, saving time, because if you call them you have to wait. They go... Because they don't have their master book there. Sometimes

		they tell me they are going to their car to get the master book and then you have to wait for them and then they ring back. They look for it and they ring back. So, it's a waste of time for me. So, if they tell me I write it down and next time I don't need to call them and I carry on with it. • Beth: 62:19: cleans patient's lines (catheter) and removes heparin while machine is priming. Tasks in parallel. • Quicker way of doing it would be nice: Alice: "Would be nice maybe to find a way of being able to do it quicker. A quicker way of doing it, maybe you only have to do an hour everyday, but I guess maybe, when I first started on dialysis twenty years ago, it was ten hours twice a week, so it's down to two and a half hours a day, it's progress, but would be a nice if they could find a way of doing it quicker." • Do other things during disinf, Jim: 50:41,40: does observations and gets stuff during T1. Trick is to be organized – prepares supplies/table while machine is priming: 52:7. • Gina: Doesn't use emla, anaesthetic cream for pain before needling, as feels it is a waste of time. Also optimizes on time by making sure she has everything ready around her (needles and all other supplies) so that as soon as green light appears, she can connect herself • Alex: programmed timer on machine to automatically turn on and start self-disinfection in the morning, to save him time. 41:15,7. • Tom: 66:4: patients rushing through process • Tom: with M5, if air detected in biobag, machine will pause, prolonging treatment. therefore patient may shake biobag in beginning to prevent that from happening and wasting time. 66:9.
5.	Planning Dialysis activity so as to accommodate activities of patient or carer in other systems	• If Fiona will be going out with her friends on a night she was planning to dialyse, she sets the machine before she goes out, so that when she comes back, she can have 2 hours of sleep, then get up and go on the machine when she's "fresh and [she] knows what [she's] doing." Or she can go on the machine earlier, before going out, which she prefers, because she can stay at her friend's house if she decides to, instead of having to come back home for dialysis. • On Sundays, Gina goes to church and she dialyses after coming back. • Ivan has to work around his wife's hospital appointment, e.g. on Mondays he goes on the machine late as he takes her for a blood test. He prefers to dialyse in the morning, to "get it over with" and have the rest of the day for himself. Also, this allows him to have a big

		meal for lunch, after dialysing (he cannot have big meal before dialysis). Otherwise, he has to wait a while before dialyzing, or will have to have a big meal late in the evening. • Bob likes to do some DIY and gardening in the morning and then dialyse in the afternoon. But the problem with this is that he finishes dialysis at 6 p.m., and is then too tired to do prayers. So he changed to dialysing in the morning at 5 a.m., after doing his prayer at 4 a.m., so that he can rest in the morning and do his prayers in the afternoon. • Bea: time of dialysis depends on what's on on that day:43:31,43:8,43:37(babysitting) • Garry: 48:3: tries to get day off in sync with wife, who is police officer and does shift work, works 3 weekends in 5 • Garry: 48:8: dialysis wipes you out, he tried dialysing in morning then doing private work, didn't work well. So now he works days and dialyses in evening. • Ida: 49:4,9: carer has had to reduce work, and dialysis fits around carer's work times • Ida: 49:15: carer always worried, hard to concentrate and do work in first 2 months • Jim: 50:8: plan dialysis in consultation with carer, arrange time • Kevin: 54:11,29: plans dialysis based on work hours (does shifts). Pretty much work, dialysis, sleep. Middle shifts are very difficult. • Beth: 62:17: can go 3 days straight without dialysis, if she is going somewhere on weekend. Plans dialysis based on what she will be doing on weekend. • Alice: if she wanted go out this evening, she would have to come from work and put herself straight on it and come off in time to go out. • Eva: 67:17: leaves weekend free so son can go to gym • Eva: 67:19: Adapted dialysis to work day • Abi: 58:18: planning dialysis depending on mum's work and on what she wants to do in the day
6.	Planning dialysis time so as to not disrupt HS activity	• Machine noise and alarm can disturb others, and that influences Adam's decision of when to dialyse. His young son has to go to bed early and Adam does not want to disturb him. Tries to finish everything, disinfection, and turn off machine by 8:30 pm maximum.
7.	Extra planning required due to dialysate batch preparation problem with M3	• Need to plan in advance, e.g. Garry: 48:51 • Same for Ida • Same for Kevin: 54:29
8.	Dialysing very early in the morning (odd time for technician)	• Ted: 56:5: 1 patient gets up at 5 am, and dialyses for 2 hrs. thatís how she copes with it, getting it done. Then sleeps again. Tech knows since he got call from her once at 5 am, on beeper, and asked her what youíre doing at this time. it was water pressure alarm

		• Similar example from Carl and Terry. Incident in which Carl wanted to do dialyse at 5 am, had problem with machine, but couldn't get support from technician.
9.	Differences to typical temporal layout	• Fiona: She sets the machine (lines) first, then heat disinfects later just before going on, followed by priming. Then during heat disinfect (and priming), sets dressings, things like line, needles and stuff, get them ready. • Some prepare take-off things in beginning, while others start preparing close to end: Cindy: Gets everything ready that she will need before and after dialysis, so doesn't have to go searching around for stuff • Beth: 62:20: sometimes doesn't do heat disinfect of RO immediately after machine disinfection finished, too late. So does it next morning before going to work, starts it. Has to turn off machine and disconnect it from RO, otherwise heat from RO, during heat disinfection, could damage machine • Eva: checks blood pressure of patient every 20-30 mins in last 1.5 hrs of treatment. 67:13.

E.22 Temporal Assignments to Tasks

Table E.22: Interaction strategies and issues related to temporal assignments to tasks

	Strategy/Issue	Example(s)
1.	Remembering to do task by keeping it on same day	• Carl: Does special shorter cleaning (programme 1) with citric acid, every Tuesday, keeps it every Tuesday. "See, like every Tuesday, I do the... what do you call it – I do programme one every Tuesday, okay, so I don't forget. I keep it every Tuesday." • Bea: takes epos every Friday, like when trained in unit, kept it same • Bea: does bloods first Monday of every month. 43:41. • Erica: usually does weekly disinf wed night after dialysis. Marks it on calendar, but has got into routine of knowing what needs to be done on a wed or on a thurs. every time they fill dialysis sheet, need to put date, then look up at cal to see date, then also see other stuff that needs to be done on that day. • Felix: does disinf once a month, beginning of every month. 47:35. • Garry: weekly beach every Sunday: "IV So, how do you remember to do these things, like...? IE I just do it every Sunday." 48:38. • Ida: doesn't mark weekly disinf on calendar, as does it every Sunday as a routine. "We don't actually have in here the disinfecting, because you do that regularly, usually on a Sunday, don't you? So we don't actually make a note of... And then we make a note in here when we have a new pack and things like that, don't we? So, yes, we, so if we need to we use the calendar but we're sort of in the routine now though, aren't we? We, but to start with it is hard, you need to have notes or you'd never know where you are really." 49:46. • Ida: need to wipe blood detector once a month, always does it usually on the first of the month. 49:55. • Jim: tends to do heat disinf of water unit on Wed, which is his off day, if they're not going out. Then also does a deep clean, including floor and machine, give everything a bit of a clean. 50:30. • Kevin: all in his head, in terms of specific days. "IE It's all in my head really. Iron I do on a Sunday, Aranesp I do on a Thursday. IV So, you keep them on the same day? IE Yes." 54:23,37. • Carl: On Tuesday patient takes aranesp (hormones), on Thursday iron. Iron used to be every week, now alternate weeks. Assigning specific days helps him remember. 39:24,26. • Abi: keeps degreasing to wed or thurs,

		depending on which day dialysis. "So I always remember that because you do it a specific day." Softener renegeration wed and sun. same with heat disinfect on RO. "IV You don't need a calendar or something like that in your case? 00:55:16 IE No, no, because I always do it on a Wednesday and Sunday, yes." 58:63,65. • Eva: 67:40: she thinks her son remembers cleanings/disinfections by doing them on Monday • Beth: 62:20: heat disinfection of RO every Monday and Friday
2.	Enforcing routine through other medium of DCog	• Bea: having a calendar for knowing when to take iron. 43:29. For knowing when to do special disinfections. 43:52. • Jim: calendar for tasks • One patient also has two calendars, one maintained by patient, with some tasks, other maintained by carer with other tasks (combination with social distribution) • Erica: calendar for tasks: 45:18. • Felix: has calendar for tasks • Several other patients have calendar too
3.	Machine alleviating need for routine	• Garry: pack of filters (comes in big black cartridge) needs to be primed and changed every month, but machine will tell you when it's last batch: "IE It tells you on the machine if it's the last one, it lasts about four weeks usually, so, then you have to… you have to just take it out." 48:43.
4.	Patient sometimes forgetting to do disinfection	• Bea: does weekly disinf when she remembers to, forgets sometimes to do it, but engineer said it's not a problem (prob as long as she does it at some point). She marks on calendar on slot for Sunday what disinfection number needs to be done this week (e.g. 5 this week), but then does it on a day when she will be staying in, not specific day. 43:51,52.
5.	Routine by association: associating task to be remembered with other task which has solidly established routine	• Bob takes medications together with breakfast • Some other participants do above too • Kevin: 54:23,37. Does injection on day he will dialyse, associates task of injection with task of dialysis.
6.	Routine by association leading to problem	• Because of associating medication with breakfast, Bob was taking blood pressure pill at wrong time. Carl: Nancy asked that patient doesn't take bp pill before dialysis in morning, after breakfast, with other medications, as that lowers his bp and not good as his bp will drop during dialysis anyway, and effect of pill will make it more. Pill is to lower bp (patient has high bp). "Obviously, before dialysis, it's a good idea for them to have their breakfast, you know, because you do become weak. So 00:28:14 when he takes his breakfast, he used to take all his medication, and he would take his

		blood pressure medication. But, you know, it's advisable for all dialysis patients to take the blood pressure tablets afterwards, yes, because your blood pressure always drops, anyway."
7.	Low-level routine of carer relying on temporal ordering of item manipulation to remember to do steps	• Carl: Lower-level routine helping carer to remember procedure for dialysis (the temporal ordering of the items that need to be manipulated serving as the reminder, rather than the steps themselves): "You know, like from morning to evening I've got a routine, it's always the same. If my mum wants to contact me, say, two 'o clock, she would know where I am, you know, so I'm a person of… So it's the same with the machine, you know. I've got a routine, you know; I know what to… the saline bag first, then the dialyser, okay, okay, so I've got a systematic way of doing things, you know." 17:48.
8.	Routine for different dialysis durations	• Jill: doing 4.5 hrs on Sun and Mon, and 5.5 hrs on Wed and Fri.25:13.

E.23 Dealing with Anticipated Problems

Table E.23: Interaction strategies and issues related to dealing with anticipated problems

	Strategy/Issue	Example(s)
1.	Result of early task feeding to decision-making in potential event	• Carl measures Bob blood sugar level half an hour before dialysis. 17:22. • Erica: measures blood sugar halfway through dialysis, to know whether she needs to drink some lucozade, as it often drops during dialysis. Feels a different feeling when low bp and when low bs, so she can tell difference (therefore doesn't measure bs before dialysis, to understand future symptoms, unlike Carl. Carl is carer of elderly dad, whereas she cares for herself, so prob has better understanding of symptoms)
2.	Second attempt at task which has chance of failure or to have more time to deal with problematic situation	• Garry: 48:22. Prepares batch overnight, in case problem, and he can attend to it and prepare another one, instead of leaving it for the day. During day he won't be here, at night he can hear if alarm and do something. Ida do something similar, check! • Bea: preparing tray on previous day already, in case she is short on some supplies and will need to get more of them tomorrow before dialysing. 43:24. • Ida: 49:72: doing batch early because of failure • Kevin: 54:27: sometimes, when machine broken, he prepares batch overnight instead of like normally during day (and then sleeps upstairs in spare room, because of noise): he drains it and starts another batch asap, to see if it is going to work. if batch works, he dialyses that evening.
3.	Planning interaction in anticipation of low cognitive resources	• Jill: in the past, she could come off at 8 or 9 and was fine, but now she's so tired that she's likely to make mistakes, so feels safer coming off when she's not too tired. So she's careful about starting at 11, she's more likely to be able to deal with things earlier in the evening. Later she's too exhausted and would make errors. Example of error she made when tired: other day she put her syringe in and didn't screw it properly (her fingers get bad, sort of fiddly work and she doesn't do it properly, or she's tired and can't concentrate), so when she pulled that out all this air was coming, and she wasn't thinking and she pushed, and you shouldn't push when you've got air like that (nothing happened, air detector in machine) • Fiona: if she knows she will be on machine tonight and she will be going out tonight with friends, she sets machine before she goes out, so when she comes back, she can have 2hrs sleep, then get up and go on machine when she's fresh and knows what

		she's doing...sometimes if she goes out with friends and feels tired and won't be able to concentrate, she might just set up machine when she gets back, and then next morning when she's fresh she will look at it and see that it's set properly and then go on it. She'd rather not come back from a night out and then forget what to do...If she'll go out, she can either go on it early or as soon as she gets back. Prefers to go early, so that if she ends up deciding to stay at her friend's house, she can do that, instead of having to come back for dialysis. • Alex: prepares box with items for next dialysis already, to save him time next morning, and to save him having to walk around the machine (he's not very steady on his feet and he could fall over), and to not have to do that first thing in the morning when he's half asleep. 41:16.
4.	Having increased readiness for particularly problematic situation	• Carl: ambiguity on things that don't happen often, e.g dealing with BP drop, he is uncertain about that, and asked the nurse to write something for him. His strategy to avoid dealing with that situation, is to come an hour before taking him off, because that's when there's likely to be a problem, and to start monitoring his BP, to make sure it doesn't get to that stage when it can be a huge problem. • Eva: if carer has to leave house, does so in beginning of treatment, as he knows that's usually less critical. 67:15.

E.24 Distribution of a Task Plan

Table E.24: Interaction strategies and issues related to distribution of a task plan

	Strategy/Issue	Example(s)
1.	Forgetting a step when rushing	• Carl: before he used to start getting ready 5 mins before coming off. Now he does it 20 mins before, and takes out everything that is needed (syringes, wipes) and puts it onto table close to machine, and he knows where everything is. He does it very early to make sure he doesn't miss anything.17:20. • Tom: common probs: putting line sets on too soon, not waiting for machine to complete a process before they do something. Then machine alarms, as it is running of processes, and alarms if taken out of its process. Could be patient rushing through it, or forgot something in procedure of coming on or off. 66:4. • Adam: forgets to inject anticoagulant as he rushes

E.25 Reducing Peak Complexity

Table E.25: Interaction strategies and issues related to reducing peak complexity

	Strategy/Issue	Example(s)
1.	Preparing tray in advance	• Gina, after dialysis likes to prepare tray for next session already, to have one less thing to do when preparing for next session • Alex: "I've set everything up from the previous dialysis, my wife helps me as well, so everything is ready to start, to line the machine up… and we set up the things that we need – you know the saline and the filter and everything for tomorrow – and that's it, basically it… So why do you prepare the tray in advance for the next time? IE No, to save me time…It's simple." 41:8,12,16. • Bea: prepares tray for next session already, during post-disinfection, fills it up with supplies. She does it, because she may have very few citra-lock and heparin left, and these she needs to go to the hospital to get more of them, not delivered by suppliers. By preparing tray in advance, she will know if she needs to get more. "So I put that in the come off box, but then if I haven't got one, then I shall go on dialysis tomorrow and then realise that I haven't… you know, I need Citra-Lock. So… but I know now that I've only got about six there and I'll have to go to the hospital to replace… get some more to replace them. IV So it's having to make sure in advance that you've got the things that you need. IE Yes, because once you're on, you know, unless you do come off, which I don't recommend, I'm stuck" 43:24. • Jill also prepares tray in advance.
2.	Infection risk with preparing tray in advance?	• Erica: 45:7: doesn't prepare in advance for next dialysis, as table needs to be disinfected before anything is put on it and if they'd put stuff already now on the table for next dialysis, would just sit there open to bugs, etc…
3.	Doing machine disinfection in advance	• Bea: disinfects and lines every morning, regardless of whether she will dialyse in the morning. If she will, she goes straight on it after. If she will dialyse in afternoon, she switches it and water unit off, then she comes back later, and it would have been already disinfected and lined, "all ready for when I do dialyse", she just has to do the test. 43:13,15,16. • Ivan: Cleans it after dialyzing, so it's ready to go the next day. "When I've finished I put it on clean, and I go and have my dinner and let it clean on its own, and then it tells me when it's finished, and then the next day when I come in I just turn it on, and it's all cleaned and ready to go."…"I clean it before it's left,

		so it's really ready to go the next day." 22:44,51.

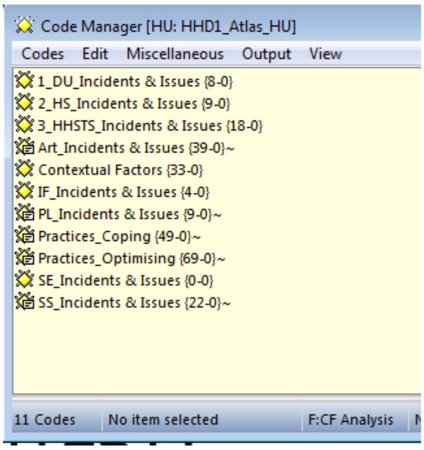
E.26 Time for Action

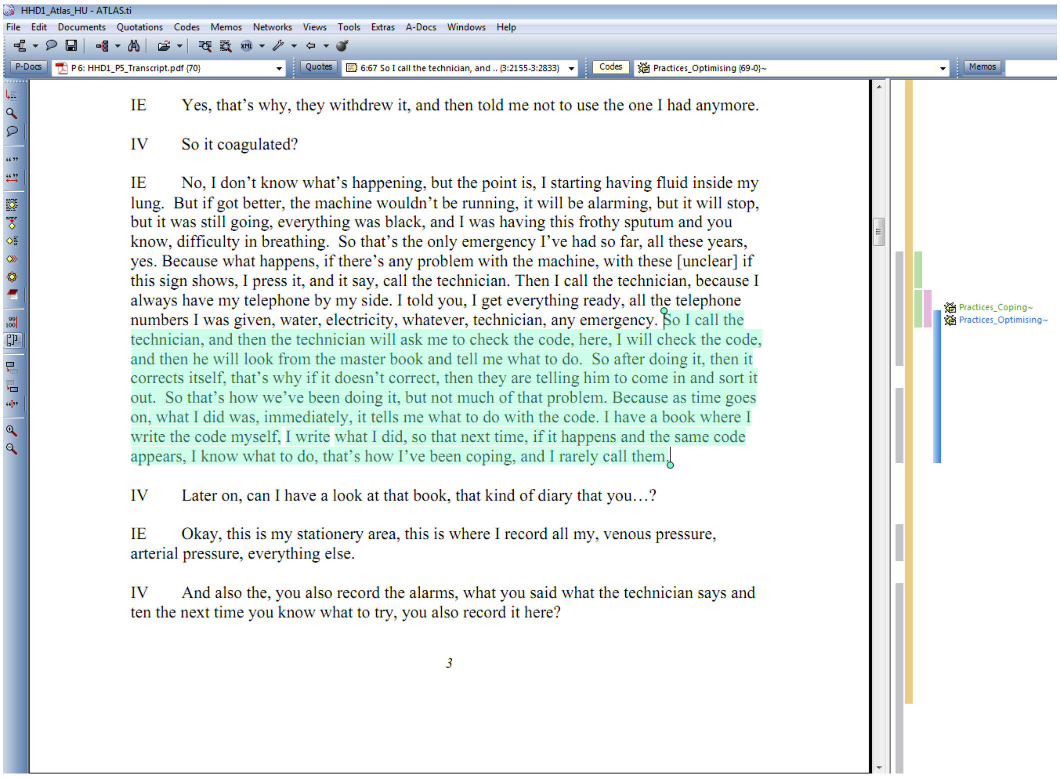
Table E.26: Interaction strategies and issues related to time for action

	Strategy/Issue	Example(s)
1.	Spatiotemporal cue	• Fiona knows when to take some medications based on where they are kept. Medications that she has to take in morning before breakfast or in evening are kept on top of dialysis machine. Ones she takes "every day" are on top of microwave in kitchen. 29:15, 32:2,3. • Jill places her weighing machine and blood pressure monitor depending on when they are used. Jill: keeps weighing machine in bedroom, because she always weighs herself just before changing into her dialysis clothes, and because she changes in her bedroom, she keeps machine there, under a cabinet. Keeps blood pressure monitor in living room downstairs, because she measures her bp before dialysis while she is at rest, around 10/11, before she starts faffing around with the dialysis (which affects the bp reading). Post dialysis, she weighs her bp a couple of hours later, after having rested, showered and sitting down (at the end of dialysis she is a bit panicky, tired, worked up, so not good to measure bp then). 25:49,50,51. • Gina: keeps medication that need to be taken after dialysis right next to her during dialysis. 31:14.
2.	Technotemporal cue	• Erica: 45:16. M5 tells when cartridge for disinfectant needs to be changed. • Alex: "And I have an alarm clock which wakes me up about three quarters of an hour before the end, and at that time I take my blood pressure while I'm on the machine and record it on the sheet, and then drop off to sleep again, and then another second alarm clock wakes me up about half an hour before the end, and I very, very leisurely set out the bits and pieces I need for taking myself off". IMG_1313.JPG.41:9,17. • Fiona: now that she hardly alarms anymore, she prefers to dialyse at night while she's going to bed. Sets alarm to wake her up to take herself off the machine.
3.	Sociotemporal cueing	• Several carers come to patient when it is time for a task
4.	Missing time for action	• Ida: 49:21: getting engrossed in other things and not realizing it's time to prepare for take-off • Ida: cue for take-off preparation would be useful, special since there seems to be a guidelines to not remain connected to machine when it's not circulating in the end anymore for more than 3-4 mins (to avoid complications linked to haemolysis)

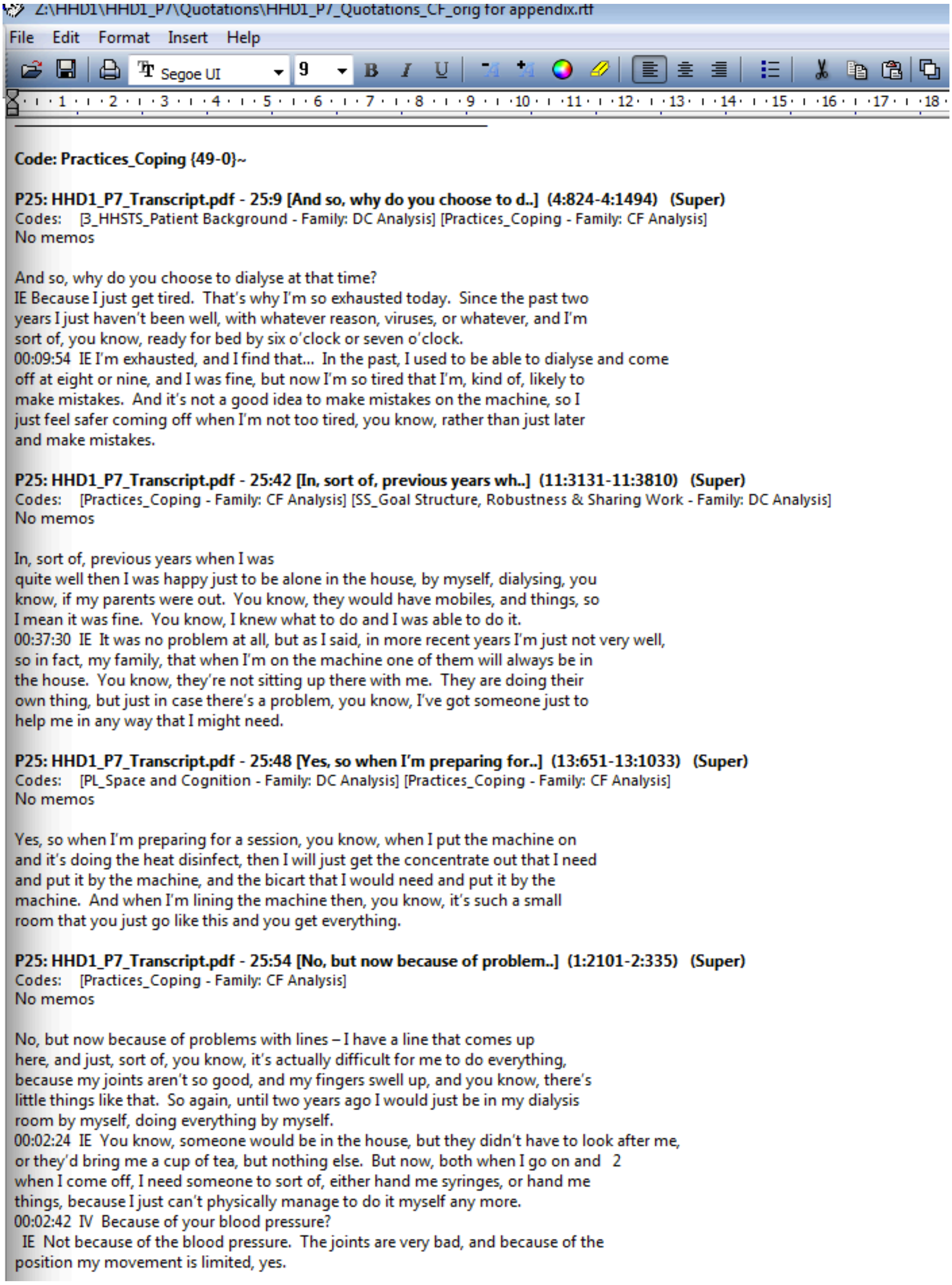
Appendix F: Methods of CFA

F.1 List of ATLAS.ti codes and example of coded interview transcript (Gina)





F.2 Example of quotations document (Jill)



Code: Practices_Coping {49-0}~

P25: HHD1_P7_Transcript.pdf - 25:9 [And so, why do you choose to d..] (4:824-4:1494) (Super)
Codes: [3_HHSTS_Patient Background - Family: DC Analysis] [Practices_Coping - Family: CF Analysis]
No memos

And so, why do you choose to dialyse at that time?
IE Because I just get tired. That's why I'm so exhausted today. Since the past two years I just haven't been well, with whatever reason, viruses, or whatever, and I'm sort of, you know, ready for bed by six o'clock or seven o'clock.
00:09:54 IE I'm exhausted, and I find that... In the past, I used to be able to dialyse and come off at eight or nine, and I was fine, but now I'm so tired that I'm, kind of, likely to make mistakes. And it's not a good idea to make mistakes on the machine, so I just feel safer coming off when I'm not too tired, you know, rather than just later and make mistakes.

P25: HHD1_P7_Transcript.pdf - 25:42 [In, sort of, previous years wh..] (11:3131-11:3810) (Super)
Codes: [Practices_Coping - Family: CF Analysis] [SS_Goal Structure, Robustness & Sharing Work - Family: DC Analysis]
No memos

In, sort of, previous years when I was
quite well then I was happy just to be alone in the house, by myself, dialysing, you know, if my parents were out. You know, they would have mobiles, and things, so I mean it was fine. You know, I knew what to do and I was able to do it.
00:37:30 IE It was no problem at all, but as I said, in more recent years I'm just not very well, so in fact, my family, that when I'm on the machine one of them will always be in the house. You know, they're not sitting up there with me. They are doing their own thing, but just in case there's a problem, you know, I've got someone just to help me in any way that I might need.

P25: HHD1_P7_Transcript.pdf - 25:48 [Yes, so when I'm preparing for..] (13:651-13:1033) (Super)
Codes: [PL_Space and Cognition - Family: DC Analysis] [Practices_Coping - Family: CF Analysis]
No memos

Yes, so when I'm preparing for a session, you know, when I put the machine on and it's doing the heat disinfect, then I will just get the concentrate out that I need and put it by the machine, and the bicart that I would need and put it by the machine. And when I'm lining the machine then, you know, it's such a small room that you just go like this and you get everything.

P25: HHD1_P7_Transcript.pdf - 25:54 [No, but now because of problem..] (1:2101-2:335) (Super)
Codes: [Practices_Coping - Family: CF Analysis]
No memos

No, but now because of problems with lines – I have a line that comes up here, and just, sort of, you know, it's actually difficult for me to do everything, because my joints aren't so good, and my fingers swell up, and you know, there's little things like that. So again, until two years ago I would just be in my dialysis room by myself, doing everything by myself.
00:02:24 IE You know, someone would be in the house, but they didn't have to look after me, or they'd bring me a cup of tea, but nothing else. But now, both when I go on and 2 when I come off, I need someone to sort of, either hand me syringes, or hand me things, because I just can't physically manage to do it myself any more.
00:02:42 IV Because of your blood pressure?
IE Not because of the blood pressure. The joints are very bad, and because of the position my movement is limited, yes.

F.3 Example of colour-coded and structured quotations document (Jill)

As the quotations in the document were analysed, quotations pertaining to the same interaction strategy/issue were coded with the same colour. After all quotations in the document had been colour-coded, quotations with the same colour-code were moved under a heading for the particular interaction strategy/issue they belonged to.

MAKING MISTAKES WHEN DIALYSING LATE DUE TO FATIGUE, TALKING TO HERSELF TO AVOID MISTAKES

P25: HHD1_P7_Transcript.pdf - 25:10 [I'm exhausted, and I find that..] (4:1134-4:1493) (Super)
Codes:[3_HHSTS_Incidents & Issues - Families (2): CF Analysis, DC Analysis]
No memos

I'm exhausted, and I find that… In the past, I used to be able to dialyse and come off at eight or nine, and I was fine, but now I'm so tired that I'm, kind of, likely to make mistakes. And it's not a good idea to make mistakes on the machine, so I just feel safer coming off when I'm not too tired, you know, rather than just later and make mistakes

P25: HHD1_P7_Transcript.pdf - 25:24 [And also, now I do get very ti..] (7:585-7:917) (Super)
Codes:[Art_Incidents & Issues - Families (2): CF Analysis, DC Analysis]
No memos

And also, now I
do get very tired and then I just, kind of, lose concentration, you know, really when I think I don't know what I'm doing, so by just keeping to…
00:20:46 IE I literally talk to myself, you know, first you do this, then you do this, then you do this, and that way I know that I'm not going to make a mistake.

P25: HHD1_P7_Transcript.pdf - 25:26 [Oh, we have, sort of, 20ml lue..] (7:2266-7:2959) (Super)
Codes:[Art_Incidents & Issues - Families (2): CF Analysis, DC Analysis]
No memos

Oh, we have, sort of, 20ml luer lock syringes, and so you align them. You don't just push them in; you screw them in, so they can't fall off by mistake. And I didn't, because, you know, my fingers get bad. It's quite, sort of, fiddly work and I don't do it properly, or I'm tired and I can't concentrate, you know, I'm not kind of… If my brain is not working properly things go wrong.
00:22:53 IE And the other day, I think I put my syringe in and I didn't screw it in properly, so when I pulled that out all this air was coming, and I wasn't thinking, and I pushed. And, you know, you shouldn't push when you've got air like that, so it's silly little things like that

P25: HHD1_P7_Transcript.pdf - 25:28 [That's why I'm so careful abou..] (8:318-8:630) (Super)
Codes:[Art_Incidents & Issues - Families (2): CF Analysis, DC Analysis]
No memos

That's why I'm so careful about getting on at, you know, 11:00, 11:30, starting the process at that time of the day, because I'm more likely to be, kind of, you know, able to deal with things earlier in the evening than later in the evening. I'm just too exhausted, and I would definitely just make errors.

P25: HHD1_P7_Transcript.pdf - 25:9 [And so, why do you choose to d..] (4:824-4:1494) (Super)
Codes:[3_HHSTS_Patient Background - Family: DC Analysis] [Practices_Coping - Family: CF Analysis]
No memos

And so, why do you choose to dialyse at that time?
IE Because I just get tired. That's why I'm so exhausted today. Since the past two years I just haven't been well, with whatever reason, viruses, or whatever, and I'm sort of, you know, ready for bed by six o'clock or seven o'clock.
00:09:54 IE I'm exhausted, and I find that… In the past, I used to be able to dialyse and come off at eight or nine, and I was fine, but now I'm so tired that I'm, kind of, likely to make mistakes. And it's not a good idea to make mistakes on the machine, so I just feel safer coming off when I'm not too tired, you know, rather than just later and make mistakes.

NEEDING HELP FROM OTHERS BECAUSE PROBLEMS WITH JOINTS

P25: HHD1_P7_Transcript.pdf - 25:17 [Not really. I mean as I said, ..] (5:2872-5:3250) (Super)
Codes:[3_HHSTS_Incidents & Issues - Families (2): CF Analysis, DC Analysis]
No memos

Not really. I mean as I said, more recently because of problems with my joints, and things, you know, sometimes when I'm just opening packs or unscrewing things my fingers, and things, are so bad that I just can't do it.
00:15:48 IE You know, just physically I can't do it, so I have to ask someone else to open something for me, but that's just because of my joints.

F.4 Example of entries of participants' interaction strategies in the spreadsheet

	A	B	C	D	F
1	No	Interaction Strategy	Participant	No of SIIs	Notes
2	1	ADJUSTING DIALYSIS TIME TO AVOID NOISE DISTURBANCE	h1p1	2	
3	2	HOME DIALYSIS NOT SAVING TIME AS EXPECTED	h1p1	1	
4	3	WATER PRESSURE PROBLEM	h1p1	3	
5	4	TRAINING WIFE TO HELP IN EMERGENCY	h1p1	5	
6	5	RUSHING DURING PREPARATION AND FORGETTING HEPARIN	h1p1	(other things on table)	
7	6	TROUBLESHOOTING PRACTICES	h1p1	2 + 1 from photo	
8	7	NEW EXTRAORDINARY SITUATIONS NOT ENCOUNTERED IN UNIT	h1p1	3	
9	8	MOVING MACHINE CLOSER TO PATIENT AND OPTIMISING SPACE USE	h1p1	5	
10	9	CHANGING SODIUM EVERY TIME	h1p1	3	
11	10	DIALYSIS LOCATION, BEDROOM, CAUSING INCONVENIENCES	h1p1	1	
12	11	ADJUSTING DIALYSATE TEMPERATURE OR KEEPING WARM	h1p1	1 (2)	not interesting at this point
13	12	USING COMPUTER DURING DIALYSIS	h1p1	1	
14	13	GETTING WIFE TO DO DISINFECTION	h1p1	3	
15	14	LINING AND PRIMING DURING DISINFECTION TO SAVE TIME	h1p1	1	
16	15	STAFF HAVING DIFFERENT WAYS OF DOING THINGS CREATING CONFUSION FOR PATIENT, NOT BEING RIGID ENOUGH, AND NOT SURE OF THINGS	h1p2	3	
17	16	MACHINE NOT FITTING IN A HOME	h1p2	2	
18	17	DEALING WITH BP DROP DURING DIALYSIS	h1p2	9	
19	18	TROUBLESHOOTING PRACTICE	h1p2	4	
20	19	FIXING ENGINEERY THINGS TO SAVE TIME AND CONTINUE DIALYSIS	h1p2	2	
21	20	DEALING WITH AIR BUBBLES DUE TO SALINE	h1p2	7	
22	21	SWITCHING TO NORMAL DISINFECTION MODE AFTER WEEKLY DISINFECTION	h1p2	2	
23	22	DEALING WITH PROBLEM WITH RO POWER SWITCH	h1p2	1	
24	23	POTENTIAL OF GETTING HELP FROM OTHERS TO DO TREATMENT	h1p2	1	
25	24	GETTING MUM TO DO DISINFECTION	h1p2	7	
26	25	OPTIMISING ON TIME AND ENSURING DIALYSIS CAN BE DONE	h1p2	2	
27	26	LIMITED KNOWLEGE OF CARER ON MACHINE	h1p2	3	
28	27	CHECKING BLOOD SUGAR TO DISTINGUISH FROM BP PROBLEM	h1p2	2	will be covered in DC temporal analysis
29	28	TRYING THINGS HE OBSERVED OTHERS DO TO TROUBLESHOOT	h1p2	2	
30	29	PATIENT KNOWING BASIC ALARM RESETS	h1p2	1	
31	30	REMEMBERING ALL THE STEPS THROUGH HAVING A ROUTINE	h1p2	1	
32	31	CHOOSING DIALYSIS TIME TO ACCOMODATE OTHER HOME ACTIVITIES	h1p2	1	
33	32	USING WALKIE-TALKIE TO COMMUNICATE	h1p2	1	
34	33	INCREASING PUMP SPEED DURING CONNECTION AND WASHBACK (TO SAVE TIME)	h1p2	2	
35	34	KEEPING MAIN STOCK IN ATTIC AND DAILY STOCK IN CUPBOARD	h1p2	1 + 1 (photo showing	
36	35	KEEPING ALL DIALYSIS EQUIPMENT, ITEMS AND SUPPLIES IN A CLOSE SPACE	h1p2	showing BP meter and	
37	36	SEEING DIFFERENT NURSES DOING DIFFERENT THINGS BUT STICKING TO TAUGHT STEPS	h1p3	1	
38	37	DIFFICULTY IN PATIENT NEEDLING SELF	h1p3	1	
39	38	TROUBLESHOOTING PRACTICE	h1p3	6	
40	39	WATER PRESSURE PROBLEM WHILE SOMEONE ELSE IS USING WATER	h1p3	1	
41	40	PATIENT NOT ABLE TO RESET ALARM DUE TO DISABILTY	h1p3	2	

F.5 Example of note in spreadsheet entry based on analysis of pictures

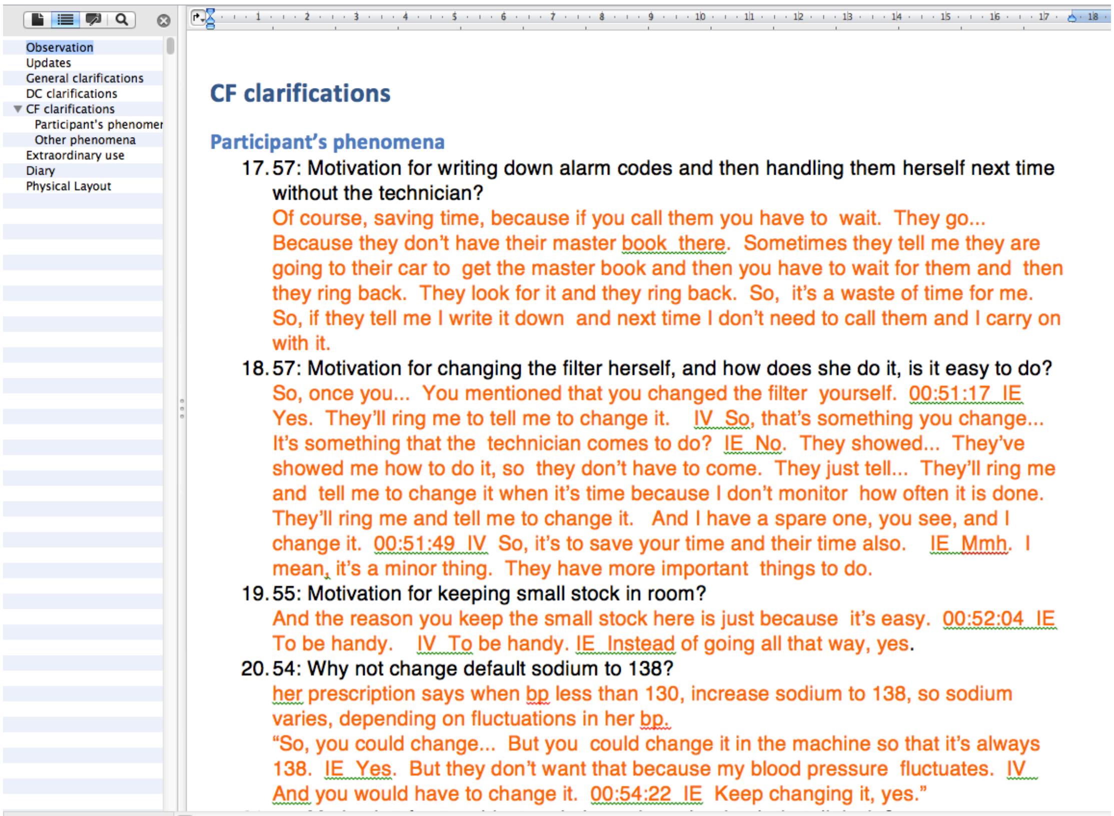
No	Interaction Strategy	Participant	No of SIIs
1	ADJUSTING DIALYSIS TIME TO AVOID NOISE DISTURBANCE	h1p1	2
2	HOME DIALYSIS NOT SAVING TIME AS EXPECTED	h1p1	1
3	WATER PRESSURE PROBLEM	h1p1	3
4	TRAINING WIFE TO HELP IN EMERGENCY	h1p1	5
5	RUSHING DURING PREPARATION AND FORGETTING HEPARIN	h1p1	4 + 1 from photo (other things on table)
6	TROUBLESHOOTING PRACTICES	h1p1	2 + 1 from photo (keeping manual on top of machine)
7	NEW EXTRAORDINARY SITUATIONS NOT ENCOUNTERED IN UNIT	h1p1	3
8	MOVING MACHINE CLOSER TO PATIENT AND OPTIMISING SPACE USE	h1p1	5

F.6 Example of points for clarification during second visit (Gina) and example of entry of clarification into spreadsheet

Acronyms used in the home visit guide

IE: Interviewee

IV: Interviewer



Observation
Updates
General clarifications
DC clarifications
CF clarifications
Participant's phenomena
Other phenomena
Extraordinary use
Diary
Physical Layout

CF clarifications

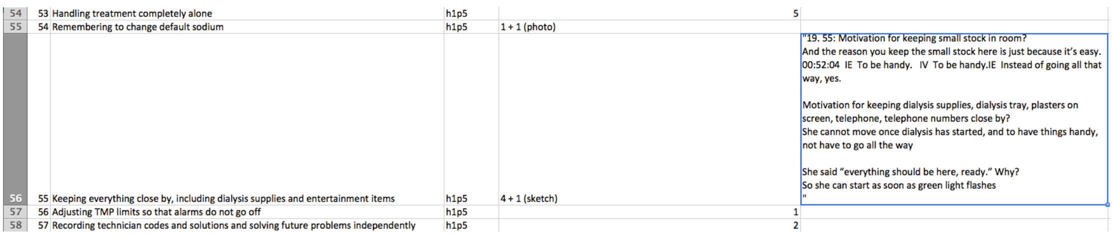
Participant's phenomena

17. 57: Motivation for writing down alarm codes and then handling them herself next time without the technician?
Of course, saving time, because if you call them you have to wait. They go... Because they don't have their master book there. Sometimes they tell me they are going to their car to get the master book and then you have to wait for them and then they ring back. They look for it and they ring back. So, it's a waste of time for me. So, if they tell me I write it down and next time I don't need to call them and I carry on with it.

18. 57: Motivation for changing the filter herself, and how does she do it, is it easy to do?
So, once you... You mentioned that you changed the filter yourself. 00:51:17 IE Yes. They'll ring me to tell me to change it. IV So, that's something you change... It's something that the technician comes to do? IE No. They showed... They've showed me how to do it, so they don't have to come. They just tell... They'll ring me and tell me to change it when it's time because I don't monitor how often it is done. They'll ring me and tell me to change it. And I have a spare one, you see, and I change it. 00:51:49 IV So, it's to save your time and their time also. IE Mmh. I mean, it's a minor thing. They have more important things to do.

19. 55: Motivation for keeping small stock in room?
And the reason you keep the small stock here is just because it's easy. 00:52:04 IE To be handy. IV To be handy. IE Instead of going all that way, yes.

20. 54: Why not change default sodium to 138?
her prescription says when bp less than 130, increase sodium to 138, so sodium varies, depending on fluctuations in her bp.
"So, you could change... But you could change it in the machine so that it's always 138. IE Yes. But they don't want that because my blood pressure fluctuates. IV And you would have to change it. 00:54:22 IE Keep changing it, yes."



54	53	Handling treatment completely alone	h1p5		5	
55	54	Remembering to change default sodium	h1p5	1 + 1 (photo)		
56	55	Keeping everything close by, including dialysis supplies and entertainment items	h1p5	4 + 1 (sketch)		"19. 55: Motivation for keeping small stock in room? And the reason you keep the small stock here is just because it's easy. 00:52:04 IE To be handy. IV To be handy.IE Instead of going all that way, yes. Motivation for keeping dialysis supplies, dialysis tray, plasters on screen, telephone, telephone numbers close by? She cannot move once dialysis has started, and to have things handy, not have to go all the way She said "everything should be here, ready." Why? So she can start as soon as green light flashes "
57	56	Adjusting TMP limits so that alarms do not go off	h1p5		1	
58	57	Recording technician codes and solutions and solving future problems independently	h1p5		2	

F.7 List of 110 interaction strategies across all 8 participants of first phase of main study

1	No	Interaction Strategy	Participant	No of SIIs
2	1	ADJUSTING DIALYSIS TIME TO AVOID NOISE DISTURBANCE	h1p1	2
3	2	HOME DIALYSIS NOT SAVING TIME AS EXPECTED	h1p1	1
4	3	WATER PRESSURE PROBLEM	h1p1	3
5	4	TRAINING WIFE TO HELP IN EMERGENCY	h1p1	5
6	5	RUSHING DURING PREPARATION AND FORGETTING HEPARIN	h1p1	4 + 1 from photo (other things on table)
7	6	TROUBLESHOOTING PRACTICES	h1p1	2 + 1 from photo (keeping manual on top of machine)
8	7	NEW EXTRAORDINARY SITUATIONS NOT ENCOUNTERED IN UNIT	h1p1	3
9	8	MOVING MACHINE CLOSER TO PATIENT AND OPTIMISING SPACE USE	h1p1	5
10	9	CHANGING SODIUM EVERY TIME	h1p1	3
11	10	DIALYSIS LOCATION, BEDROOM, CAUSING INCONVENIENCES	h1p1	1
12	11	ADJUSTING DIALYSATE TEMPERATURE OR KEEPING WARM	h1p1	1 (2)
13	12	USING COMPUTER DURING DIALYSIS	h1p1	1
14	13	GETTING WIFE TO DO DISINFECTION	h1p1	3
15	14	LINING AND PRIMING DURING DISINFECTION TO SAVE TIME	h1p1	1
16	15	STAFF HAVING DIFFERENT WAYS OF DOING THINGS CREATING CONFUSION FOR PATIENT, NOT BEING RIGID ENOUGH, AND NOT SURE OF THINGS	h1p2	3
17	16	MACHINE NOT FITTING IN A HOME	h1p2	2
18	17	DEALING WITH BP DROP DURING DIALYSIS	h1p2	9
19	18	TROUBLESHOOTING PRACTICE	h1p2	4
20	19	FIXING ENGINEERY THINGS TO SAVE TIME AND CONTINUE DIALYSIS	h1p2	2
21	20	DEALING WITH AIR BUBBLES DUE TO SALINE	h1p2	7
22	21	SWITCHING TO NORMAL DISINFECTION MODE AFTER WEEKLY DISINFECTION	h1p2	2
23	22	DEALING WITH PROBLEM WITH RO POWER SWITCH	h1p2	1
24	23	POTENTIAL OF GETTING HELP FROM OTHERS TO DO TREATMENT	h1p2	1
25	24	GETTING MUM TO DO DISINFECTION	h1p2	7
26	25	OPTIMISING ON TIME AND ENSURING DIALYSIS CAN BE DONE	h1p2	2
27	26	LIMITED KNOWLEGE OF CARER ON MACHINE	h1p2	3
28	27	CHECKING BLOOD SUGAR TO DISTINGUISH FROM BP PROBLEM	h1p2	2
29	28	TRYING THINGS HE OBSERVED OTHERS DO TO TROUBLESHOOT	h1p2	2
30	29	PATIENT KNOWING BASIC ALARM RESETS	h1p2	1
31	30	REMEMBERING ALL THE STEPS THROUGH HAVING A ROUTINE	h1p2	1
32	31	CHOOSING DIALYSIS TIME TO ACCOMODATE OTHER HOME ACTIVITIES	h1p2	1
33	32	USING WALKIE-TALKIE TO COMMUNICATE	h1p2	1
34	33	INCREASING PUMP SPEED DURING CONNECTION AND WASHBACK (TO SAVE TIME)	h1p2	2
35	34	KEEPING MAIN STOCK IN ATTIC AND DAILY STOCK IN CUPBOARD	h1p2	1 + 1 (photo showing cupboard)
36	35	KEEPING ALL DIALYSIS EQUIPMENT, ITEMS AND SUPPLIES IN A CLOSE SPACE	h1p2	machine and walkie talkies)
37	36	SEEING DIFFERENT NURSES DOING DIFFERENT THINGS BUT STICKING TO TAUGHT STEPS	h1p3	1
38	37	DIFFICULTY IN PATIENT NEEDLING SELF	h1p3	1
39	38	TROUBLESHOOTING PRACTICE	h1p3	6
40	39	WATER PRESSURE PROBLEM WHILE SOMEONE ELSE IS USING WATER	h1p3	1
41	40	PATIENT NOT ABLE TO RESET ALARM DUE TO DISABILTY	h1p3	2
42	41	TRYING SOLUTION SHE SAW IN THE UNIT	h1p3	1
43	42	HOME PHYSICAL ENVIRONMENT, TANGLE OF WIRES, LEADING TO ALARMS	h1p3	1
44	43	RECORDING ALARMS AND SOLUTIONS FOR FUTURE	h1p3	2 + 1(photo)
45	44	CHANGING FILTER HERSELF	h1p3	1
46	45	HAVING EVERYTHING READY AT HAND, INCLUDING SPARE SUPPLIES	h1p3	1
47	46	HAVING COMPUTER SCREEN (TV/DVD) IN FRONT OF BED	h1p3	1 (sketch)
48	47	RECORDING IRON&EPO, MONTHLY BLOODS, AND CCART CLEAN IN DIALYSIS CHART	h1p3	1 (photo)
49	48	Coping with immobility of machine	h1p4	2
50	49	Flexibility in choosing when to dialyse	h1p4	1
51	50	Moving machine screen close to her on the bed	h1p4	1
52	51	Optimising space allocated to the machine	h1p4	1
53	52	Recording alarms	h1p4	1
54	53	Handling treatment completely alone	h1p5	5
55	54	Remembering to change default sodium	h1p5	1 + 1 (photo)
56	55	Keeping everything close by, including dialysis supplies and entertainment items	h1p5	4 + 1 (sketch)
57	56	Adjusting TMP limits so that alarms do not go off	h1p5	1
58	57	Recording technician codes and solutions and solving future problems independently	h1p5	2
59	58	ISSUE WITH HAVING MACHINE IN THE HOME, NOT TIDY	h1p6	3
60	59	PASSING OUT WHILE ON DIALYSIS AND WIFE INTERVENING	h1p6	3
61	60	NOT DIALYSING ON WEEKEND DUE TO SUPPORT NOT AVAILABLE	h1p6	1
62	61	REMEMBERING TO CLOSE ALL CLIPS, LEAVING CAPS OPEN, AND THE STEPS TO PERFORM	h1p6	3
63	62	PROBLEM WITH UNDERSTANDING WHAT PROBLEM WITH MACHINE IS	h1p6	4
64	63	INCIDENT WITH WHEEL CRUSHING TUBE	h1p6	RO)
65	64	NOT REALLY HAVING A CARER	h1p6	2
66	65	PLANNING DIALYSIS TIME, CONSIDERING WIFE'S SICKNESS AS WELL	h1p6	1
67	66	CONFLICTING VIEWS ON PUMP SPEED	h1p6	1
68	67	KEEPING INSTRUCTIONS CLOSE BY	h1p6	1
69	68	PLANNING TO DIALYSE IN LESS TIME TO MAKE MORE OF THE DAY	h1p6	1
70	69	DOING OTHER THINGS WHILE ON DIALYSIS	h1p6	1
71	70	LEAVING PORT OPEN TO KNOW WHEN THERE'S BLOOD	h1p6	1
72	71	CLEANING AFTER DIALYSIS TO CONNECT QUICKLY NEXT DAY	h1p6	1
73	72	USING PHYSICAL SPACE OF MACHINE TO LAY PLASTERS	h1p6	1
74	73	NURSES JUST EXPLANING BASICS AND PATIENT HAVING TO LEARN MOST THINGS ON HIS OWN, DISCOVERING PROBLEMS AT HOME	h1p6	2
75	74	KEEPING TRAY, BP MONITOR, WEIGHING MACHINE, CUP OF TEA NEARBY	h1p6	2 (photo) + 1 (sketch)
76	75	KEEPING SUPPLIES ON CHAIRS AND FURNITURE NEARBY AND IN DRAWERS	h1p6	1 (sketch)
77	76	MANAGING BULKY DIALYSIS SUPPLIES	h1p7	3 + 1 (sketch) + 1 (PHOTO)
78	77	MAKING MISTAKES WHEN DIALYSING LATE DUE TO FATIGUE, TALKING TO HERSELF TO AVOID MISTAKES	h1p7	5
79	78	NEEDING HELP FROM OTHERS BECAUSE PROBLEMS WITH JOINTS	h1p7	1
80	79	PROBLEM WITH NOT EASILY DIALYSING IN UNIT WHEN HOME MACHINE IS NOT WORKING, LOSING CONFIDENCE IN MACHINE	h1p7	2
81	80	POSSIBLE SUPPORT FROM TECHNOLOGY WITH OTHER THINGS	h1p7	1
82	81	SELF-CARING, PARENTS HELPING OUT WITH EMERGENCY	h1p7	4
83	82	SPACE RESTRICTIONS AND TECHNICIAN'S ACCESS TO MACHINE	h1p7	1
84	83	RECORDING MEDICATION DATES IN DIARY TO KNOW WHEN NEXT TO TAKE	h1p7	1
85	84	KEEPING PHONE CLOSE BY AND PHONE NUMBERS ON THE WALL IN CASE OF EMERGENCY	h1p7	1 + 1 (sketch) + 1 (photo)
86	85	STICKING TO TAUGHT STEPS AS A SAFETY PRECAUTION, AND TO AVOID CONFUSION AND KEEP IT EASY TO REMEMBER	h1p7	2
87	86	RECORDING PROBLEMS IN DIARY FOR FUTURE REFERENCE, INCLUDING ALARM CODES AND SOLUTIONS, AND OBSERVATIONS WHILE ON DIALYSIS	h1p7	1 + 1 (photo)
88	87	WATCHING TV WHILE ON DIALYSIS	h1p7	1 + 1 (sketch) + 1 (photo)
89	88	GETTING MUM TO DO DISINFECTION	h1p7	3
90	89	KEEPING BP MONITOR AND WEIGHING MACHINE IN OTHER ROOMS WHERE THEY WILL BE USED	h1p7	1
91	90	UNCONFIDENT TECHNICIANS INSTILLING UNCONFIDENCE IN PATIENT	h1p7	2
92	91	KEEPING LOTS OF INFORMATION ON NOTICE BOARD: SUPPLY CALENDAR, PHONE NUMBERS, CLEANING INSTRUCTIONS, PREVIOUS DIALYSIS CHARTS, INSTRUCTIONS FOR PREPARING SOME MEDICATIONS	h1p7	5 (photos)
93	92	DOING DIALYSIS IN VERANDAH, HEATING MACHINE IN WINTER, AND STOCKING DIALYSATE IN WINTER	h2p1	3 + 1 sketch
94	93	WARMING TRAVEL DIALYSATE	h2p1	1
95	94	PARTNER OR DAUGHTER TRAINED TO INTERVENE IN CASE OF EMERGENCY	h2p1	1
96	95	PRIMING USING SYRINGE, MACHINE REVERSING FLOW WHEN BUBBLE DETECTED TO ALLOW REMOVAL WITH SYRINGE, LEAVING IT TO PRIME CONTINUOUSLY	h2p1	4
97	96	USING CLAMPS TO UNTIGHTEN LINES	h2p1	1
98	97	CHECKING STEPS WITH OTHER PATIENTS INSTEAD OF NURSE	h2p1	1
99	98	SEEING HOW MACHINE IS SET UP AT OTHER PATIENT'S PLACE	h2p1	1
100	99	GETTING OUT BOOK FOR SOME ALARM CODES, AND MEMORISING FAMILIAR ONES	h2p1	2
101	100	DIALYSING WITH ONLY YOUNG DAUGHTER AROUND	h2p1	1
102	101	TAKING (PORTABLE) MACHINE UPSTAIRS TO DIALYSE AT NIGHT	h2p1	1
103	102	DOING DAILY DIALYSIS BECAUSE SHE FEELS BETTER, DESPITE CONSTRAINTS ON LIFE	h2p1	1
104	103	UTILISING CHANCE TO FIX PRESSURE ISSUE BEFORE ACTUAL ALARM	h2p1	1
105	104	WATCHING TV WHILE ON DIALYSIS	h2p1	1 + 1 sketch
106	105	MANAGING SUPPLIES IN DRAWER NEARBY AND IN SHED	h2p1	2 + 1 sketch + 1 photo
107	106	CHANGING PRESCRIBED DIALYSATE	h2p1	1
108	107	SENDING DIALYSIS CHARTS WEEKLY INSTEAD OF DAILY	h2p1	1
109	108	SORTING OUT PROBLEMS ON HER OWN DUE TO BEING MORE INDEPENDENT AND BEING CLOSER TO HER TREATMENT	h2p1	1
110	109	TAKING (PORTABLE) MACHINE TO OTHER PLACES AND ON HOLIDAY	h2p1	1
111	110	OPTIMISING SPACE USE	h2p1	1 + 1 photo

F.8 Grouping of the 110 interaction strategies into 13 groups

1	No	Strategy Group	Interaction Strategy	
2	1	Avoiding disturbance from dialysis to home system, home system adapting to constraints posed by dialysis, taking measures to allow presence in both systems simultaneously	1	ADJUSTING DIALYSIS TIME TO AVOID NOISE DISTURBANCE
3			10	DIALYSIS LOCATION, BEDROOM, CAUSING INCONVENIENCES
4			16	MACHINE NOT FITTING IN A HOME
5			58	ISSUE WITH HAVING MACHINE IN THE HOME, NOT TIDY
6			3	WATER PRESSURE PROBLEM
7			39	WATER PRESSURE PROBLEM WHILE SOMEONE ELSE IS USING WATER
8			76	MANAGING BULKY DIALYSIS SUPPLIES
9			32	USING WALKIE-TALKIE TO COMMUNICATE
10			h1p5	dialysis in room creates privacy issue
11			h1p4	Machine corner doesn't have carpet, but tiles. Changed it so that if there is a leak, carpet doesn't get wet
12			h1p6	water pressure problem when wife starts machine washing before he dialyses
13	2	Planning dialysis so as to accommodate other home activities	31	CHOOSING DIALYSIS TIME TO ACCOMODATE OTHER HOME ACTIVITIES
14			65	PLANNING DIALYSIS TIME, CONSIDERING WIFE'S SICKNESS AS WELL
15			68	PLANNING TO DIALYSE IN LESS TIME TO MAKE MORE OF THE DAY
16			102	DOING DAILY DIALYSIS BECAUSE SHE FEELS BETTER, DESPITE CONSTRAINTS ON LIFE
17			49	Flexibility in choosing when to dialyse
18			h1p5	Planning dialysis so as to accommodate other home activities Yes. hospital appointments, going to church. Can dialyse on Sunday after church or Monday, depending on how she feels about it
19			h1p6	has to work around his wife's hospital appointments
20	3	Optimising on time spent with dialysis	2	HOME DIALYSIS NOT SAVING TIME AS EXPECTED
21			5	RUSHING DURING PREPARATION AND FORGETTING HEPARIN
22			14	LINING AND PRIMING DURING DISINFECTION TO SAVE TIME