Sharing is Caring

Integrating Health Information Systems to Support Patient-Centred Shared Homecare

MARIA HÄGGLUND
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Abstract

In the light of an ageing society with shrinking economic resources, deinstitutionalization of elderly care is a general trend. As a result, homecare is increasing, and increasingly shared between different health and social care organizations. To provide a holistic overview about the patient care process, i.e. to be patient-centred, shared homecare needs to be integrated. This requires improved support for information sharing and cooperation between different actors, such as care professionals, patients and their relatives.

The research objectives of this thesis are therefore to study information and communication needs for patient-centered shared homecare, to explore how integrated information and communication technology (ICT) can support information sharing, and to analyze how current standards for continuity of care and semantic interoperability meet requirements of patient-centered shared homecare.

An action research approach, characterized by an iterative cycle, an emphasis on change and close collaboration with practitioners, patients and their relatives, was used. Studying one specific homecare setting closely, intersection points between involved actors and specific needs for information sharing were identified and described as shared information objects. An integration architecture making shared information objects available through integration of existing systems was designed and implemented. Mobile virtual health record (VHR) applications thereby enable a seamless flow of information between involved actors. These applications were tested and validated in the OLD@HOME-project. Moreover, the underlying information model for a shared care plan was mapped against current standards. Some important discrepancies were identified between these results and current standards for continuity of care, stressing the importance of evaluating standardized models against requirements of evolving healthcare contexts.

In conclusion, this thesis gives important insights into the needs and requirements of shared homecare, enabling a shift towards patient-centered homecare through mobile access to aggregated information from current feeder systems and documentation at the point of need.

*Keywords*: health informatics, user-centred design, integrated health information systems, homecare services, cooperative work, health informatics standardization

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Till min mor,

en av alla de vardagshjältar
som arbetar inom äldreomsorgen
och som inspirerat mig i mitt arbete
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<tr>
<td>AN</td>
<td>Assistant Nurse</td>
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<td>ANSI</td>
<td>American National Standards Institute</td>
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<td>CDA</td>
<td>Clinical Document Architecture</td>
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<tr>
<td>CEN</td>
<td>European Committee for Standardization, Comité Européen de Normalisation, Europäische Komitee für Normung</td>
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<td>CEN/ISSS</td>
<td>CEN’s ICT sector activities</td>
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<td>CIS*</td>
<td>Common Information Space</td>
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<td>CPR</td>
<td>Computer-based Patient Record</td>
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<td>CSCW</td>
<td>Computer Supported Cooperative Work</td>
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<tr>
<td>DN</td>
<td>District Nurse</td>
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<tr>
<td>DICOM</td>
<td>Digital Imaging and Communications in Medicine</td>
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<tr>
<td>EDIFACT</td>
<td>Electronic Data Interchange for Administration, Commerce and Transport</td>
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<td>EHR*</td>
<td>Electronic Health Record</td>
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<tr>
<td>EMR*</td>
<td>Electronic Medical Record</td>
</tr>
<tr>
<td>EPR*</td>
<td>Electronic Patient Record</td>
</tr>
<tr>
<td>EN</td>
<td>European Standard, Norme Européenne, Europäische Norm</td>
</tr>
<tr>
<td>ENV</td>
<td>European Prestandard, Prenorm europäische Vornorm</td>
</tr>
<tr>
<td>FHCNR</td>
<td>Federated HealthCare Record</td>
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<tr>
<td>GP</td>
<td>General Practitioner</td>
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<td>GEHR</td>
<td>Good European/Electronic Health Record</td>
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<tr>
<td>GUI</td>
<td>Graphical User Interface</td>
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<td>HCI</td>
<td>Human Computer Interaction</td>
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<td>HHS</td>
<td>Home Help Service (Personnel)</td>
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<td>HI</td>
<td>Health Informatics</td>
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<td>HI-U</td>
<td>Health Informatics and Usability</td>
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<td>HIS*</td>
<td>Health Information System</td>
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<td>HL7</td>
<td>Health Level Seven</td>
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<tr>
<td>ICT</td>
<td>Information and Communication Technology</td>
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<tr>
<td>IEEE</td>
<td>The Institute of Electrical and Electronics Engineers</td>
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<tr>
<td>IHE</td>
<td>Integrating the Healthcare Enterprise</td>
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<td>IS</td>
<td>Information System</td>
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<td>ISO</td>
<td>International Organisation for Standardization</td>
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<td>ISSS</td>
<td>Information Society Standardization System</td>
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<tr>
<td>MdTS</td>
<td>Multi-disciplinary Thematic Seminars</td>
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<td>MI</td>
<td>Medical Informatics</td>
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<tr>
<td>MIME</td>
<td>Multipurpose Internet Mail Extensions</td>
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<td>NHS CfH</td>
<td>National Health Service – Connecting for Health</td>
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<tr>
<td>PD</td>
<td>Participatory Design</td>
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<tr>
<td>PDA</td>
<td>Personal Digital Assistant, handheld device</td>
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<tr>
<td>RIM</td>
<td>Reference Information Model</td>
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<tr>
<td>RM</td>
<td>Reference Model</td>
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<tr>
<td>SOA</td>
<td>Service-Oriented Architecture</td>
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<td>SEHR</td>
<td>Shared Electronic Health Record</td>
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<tr>
<td>TC251</td>
<td>Technical Committee 251, the CEN committee</td>
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<tr>
<td>UCSD</td>
<td>User Centred Systems Design</td>
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<td>UI</td>
<td>User Interface</td>
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<tr>
<td>UML</td>
<td>Unified Modeling Language</td>
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<td>VHR*</td>
<td>Virtual Health Record</td>
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<tr>
<td>WLAN</td>
<td>Wireless Local Area Network</td>
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<tr>
<td>XML</td>
<td>eXtensible Mark-up Language</td>
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* This concept is further described under Definitions
Definitions

*Architecture* - the fundamental organization of a system, embodied in its components, their relationships to each other and the environment, and the principles governing its design and evolution (IEEE Std 1471-2000 2000). An architectural model of a distributed system is concerned with the placement of its parts and the relationships between them. Examples are the *client-server model* and the *peer-to-peer model* (Coulouris, Dollimore et al. 2005).

*Asynchronous communication* - a mode of communication between two parties, when the exchange does not require both to be active participants in the conversation at the same time, such as sending a letter (Coiera 2003).

*Care plan* – description of planned and duly personalized *activities bundles* addressing one or more *health issues*. Each bundle encompasses all *health care activities* to be provided to a *subject of care* by one or several *health care professionals* having the same healthcare professional entitlement (EN13940-1 2007).

*Collaborative or cooperative work* – a designation of multiple persons working together to produce a product or service (Bannon and Schmidt 1989). Bannon and Schmidt continue to state that the boundaries of cooperative work networks are defined by actual cooperative behavior and are not necessarily congruent with the boundaries of formal organizations. A cooperative work process may cross corporate boundaries and may involve partners in different organizations at different sites, each of the partners providing a component of the full service or product (Bannon and Schmidt 1989). In this thesis, the terms collaborative work and cooperative work are used as exchangeable.

*Common information space* – a concept introduced by Schmidt and Bannon (Schmidt and Bannon 1992) and further explored by Bannon and Bødker (Bannon and Bødker 1997) which stresses that information is not simply shared, but needs to be explicitly *placed* in common. Information has to be extracted from one person’s work context and reformulated in some way that displays its relevance to others, by for instance some common conceptual scheme (Reddy, Dourish et al. 2001). A CIS incorporates not only a repository of information held in common amongst different parties, but also the work practices surrounding that information – how it is used, managed and integrated into the work of those who share it. In the OLD@HOME project, we used the term *Shared information objects* with a similar meaning.
Continuity of care – an organizational principle, where one or more healthcare providers deliver several healthcare services to a subject of care. This organizational principle focuses on the time related links between those different services (EN13940-1 2007).

Distributed systems – a system in which components located at networked computers communicate and coordinate their actions by passing messages (Coulouris, Dollimore et al. 2005).

Electronic Health Record – in this thesis the term is used as a general concept representing an electronic record, used by one or more care professions, but without distinguishing between integrated and non-integrated solutions. In this sense, the term EHR includes other concepts commonly used such as Electronic Medical Record and Electronic Patient Record.

Health Information Systems (HIS) – the acronym HIS has often been used meaning Hospital Information Systems (Clayton and van Mulligen 1997). However, over the years a shift in focus has brought a new meaning to the acronym, namely Health Information Systems, whereof Hospital Information Systems are only one instance (Haux 2006a). Health information systems can be defined as comprising all computer-based components which are used to enter, store, process, communicate, and present health-related or patient-related information, and which are used by healthcare professionals or patients in the context of inpatient or outpatient care. (Ammenwerth and Keizer 2005)

Integrated care – an organizational principle, encompassing at the same time each of continuity of care, shared care, and seamless care (EN13940-1 2007).

Integration – in relation to information systems integration means the combination of diverse application entities into a relationship which functions as a whole (Saranummi, Piggott et al. 2005). The term integration can also be used to signify the relationship between diverse organizational entities working together as one unit, for example in integrated care.

Interoperability – a state which exists between two application entities when one application entity can accept data from the other and perform the required task in an appropriate and satisfactory manner, without the need for additional operator intervention (Saranummi, Piggott et al. 2005). Interoperability can be divided into different levels. Syntactic interoperability is the ability of two or more systems to exchange information that has the same structure, or syntax, but carries no assurance that the meaning will be interpreted identically by all parties, whereas semantic interoperability deals with meaning, guaranteeing that the meaning of a structure is unambiguously exchanged (Mead 2006).

Intersection point – a situation and setting where different actors involved in a cooperative process, such as shared homecare, interact and/or exchange or share information.

Middleware – is a layer of software whose purposes are to mask heterogeneity and to provide a convenient programming model to application programmers. Middleware is represented by processes or objects in a set of
interacting computers. It is concerned with providing useful building blocks for the construction of software components that work with one another in a distributed system (Coulouris, Dollimore et al. 2005).

**Patient-centred care** – in relation to shared care is a care model that allows all involved actors to have an integrated view of the entire patient care process. In this sense, shared care needs to be integrated in order to be patient-centred. The concept also addresses a shift in the relationship between patients and care providers (Stewart 2001).

**Platform** – the lowest-level hardware and software layers often referred to as a platform for distributed system and applications. These low-level layers provide services to the layers above them. Each layer is implemented independently into a computer, bringing the system’s programming interface up to a level that facilitates communication and coordination between processes (Coulouris, Dollimore et al. 2005).

**Seamless care** – a quality principle, focusing on the timely and appropriate transfer of activity and information. This applies when responsibility for the delivery of healthcare services is entirely, or partly, transferred from a healthcare provider to another (EN13940-1 2007).

**Shared care** – an organizational principle where two or more healthcare providers jointly cooperate to provide healthcare services to a subject of care for a continuing health issue. This organizational principle focuses on joint objectives and responsibilities (EN13940-1 2007).

**Shared care plan** – a care plan that is adapted to specific needs of shared care, giving access to planned interventions from different care provider organizations. It may also include self care interventions and active participation of patients and family carers.

**Shared prescription list** – a list of a patient’s current medications, including additional comments and instructions related to the administration of the medication. The shared prescription list could also be referred to as a shared medication list, or medication record.

**Subject of Care** – a person, or other living subject, seeking to receive, receiving, or having received healthcare activities (EN13940-1 2007). In this thesis the concept *patient* is used instead of subject of care, except in sections addressing standards using the term subject of care.

**Synchronous Communication** – a mode of communication when two parties exchange messages across a communication channel at the same time, for instance using telephones (Coiera 2003).

**Virtual Health Record** – a solution that provides users with an integrated view of information stored in different health information systems in different locations.
1. Introduction

Most developed countries are facing an increased demand for health and social care. This is due to a number of factors;

- **demographic development**, with the old age dependency ratio in Europe expected to double by the middle of this century, and the number of persons aged 80 and over is expected to nearly triple by 2051 (Lanzieri 2006),
- **economic development**, with increased expectations on the quality of healthcare systems combined with public health services having to cope with financial resource constraints and shortage of skilled labor (Cabrera, Burgelman et al. 2004), and
- **societal development**, with an increasing number of elderly persons living alone, and increasing mobility in society resulting in families distributed over large geographical areas (Koch 2008).

In addition, advances in medical informatics and engineering also affect organization and provision of care. New treatments and technological solutions change both the need for different types of care and the possibilities of providing care in different settings (Stoeckle 1995). For example, advances in medical technology enable surgical procedures to become less invasive, and provide solutions for monitoring patients from a distance, thereby enabling patients to receive a greater part of the treatment in a home or primary care setting, and consequently increasing the need for this type of care.

Such economic, political, socio-demographic advances in medicine as well as health informatics and medical engineering have moved modern healthcare beyond a largely reactive acute care paradigm towards a more holistic paradigm, emphasising optimisation of the population’s health (Shortell and Kaluzny 2006). At the core of this shift is a movement away from episodic treatment of acute health issues to provision of coordinated services that will provide continuity of care for those with chronic conditions and enhance the health status of defined populations (Epping-Jordan, Pruitt et al. 2004; Wagner, Bennett et al. 2005; Strandberg-Larsen, Nielsen et al. 2007). As a result, provision of healthcare is increasingly shared between different healthcare and social care organizations. In addition, the transition from hospital to community care is a general trend (Coiera 2003, p. 268) and the deinstitutionalization of elderly care is part of this pattern (Jacobzone 2000), leading to an increase in homecare.
As responsibilities for providing healthcare are increasingly shared between different organizations, there is also an increase in awareness of the need for integrated care (Alaszewski, Billings et al. 2004; Reed, Cook et al. 2005; Haux 2006b). Integrated care can be defined as an organizational principle, encompassing continuity of care, shared care, and seamless care (EN13940-1 2007). Important aspects of integrated care that will be focused on in this thesis are cooperation between healthcare providers to jointly provide healthcare services to a patient, and timely and appropriate transfer of activity and information between healthcare providers. The term patient-centred care is used to describe current changes, in form of a shift from organisation-centric to patient-centric provision of healthcare and to strengthen the role of patients and family carers in this process (Wagner, Bennett et al. 2005).

The work situations of healthcare professionals are also affected by these developments, shifting towards more mobile, flexible and information and knowledge intensive environments. However, communication between clinicians about co-treated patients has for a long time been considered delayed, incomplete, or erroneous (Branger, Duisterhout et al. 1997). More recently Bodenheimer provides an overview of problems regarding care coordination between different care providers and between care providers and patients and their relatives (Bodenheimer 2008), confirming that this remains a problematic issue to this day.

Long-term care of elderly people is identified as an area where the need for integrated care is great (Alaszewski, Billings et al. 2004; Leichsenring 2004). As life-expectancy is rising, so are chronic conditions and the need for long-term, cross-institutional care. Older people tend to experience higher rates of chronic illness such as diabetes, heart disease or disability associated with strokes, and when they experience an acute episode of illness, treatment is more complex and recovery and recuperation often slower and longer (Alaszewski, Billings et al. 2004). At the same time, future generations of elderly patients will have higher expectations on healthcare services and will most likely want to maintain their mobile lifestyle while choosing their form of care and care provider organization based on individual preferences. Family carers often take great responsibility in the provision of care for elderly patients (Magnusson 2005), and despite cultural diversity of the roles of family carers in Europe (Alaszewski, Billings et al. 2004), their importance needs to be recognised (Nankervies, Waxman et al. 2002). Regardless of what societal changes may bring, patient participation and empowerment are regarded as primary conditions for good care (Wallerstein 2006) and are in need of improvement (Wagner, Bennett et al. 2005).

Health information systems (HIS) are often suggested as a means to improve cooperation and coordination of work in shared care (Branger, Duisterhout et al. 1997; Andersson, Beck-Fris et al. 1999; Andersson, Hallberg et al. 2003; Bricon-Souf, Anceaux et al. 2005). It has been widely recognized that HIS must be designed with consideration of information require-
ments, cognitive capabilities and limitations of the end-users, as well as considera-
tions of daily work and organizational specific processes and practices

A key issue in supporting cooperation and collaboration required in to-
day’s healthcare systems is the need for information sharing between differ-
ent care providers. Today, shared patient care is hampered due to the exis-
tence of numerous HIS, in form of island solutions or even paper-based sys-
tems. To achieve a seamless and secure information transfer between differ-
ent HIS, different levels of interoperability need to be considered. Syntactic
interoperability is the ability of two or more systems to exchange informa-
tion that has the same structure, or syntax, but carries no assurance that the
meaning will be interpreted identically by all parties, whereas semantic in-
teroperability deals with meaning, guaranteeing that the meaning of a struc-
ture is unambiguously exchanged (Mead 2006). Documents containing
health related information rely on the specificity of medical vocabularies and
common practice to guarantee correct conveyance of meaning (semantic interopera-
bility) between healthcare professionals. Semantic interoperability
between HIS requires that the meaning of data is unambiguously exchanged
between HIS, which does not necessarily mean that all systems have to proc-
ess the data the same way, but that each system will make its processing
decisions based on the same meaning as formally defined domain concepts
(Mead 2006). Syntactic interoperability must be achieved to be able to ex-
change information between HIS in the first place, but semantic interoper-
bility is also important, and a much more complex goal to achieve.

Several important attempts have been made worldwide to solve the prob-
lems of HIS interoperability, as will be discussed further in section 2.3 Inte-
gration and interoperability. The results of such work need to be examined
to determine whether they meet the requirements of patient-centred shared
homecare, where information needs to be shared between health and social
care, as well as with patients and relatives.

1.1 Research objectives

In order to support provision of patient-centred shared homecare through
ICT, it is necessary to study the context in which the ICT is to be used. Issues,
problems and needs as they are experienced by health and social care
professionals, patients and family carers in real clinical settings must be
explored.

In order to improve information sharing it is also of great importance to
address interoperability issues. I therefore choose to approach the problems
described above from two perspectives, first of all to explore a real clinical
setting where care is shared between many different actors to elicit detailed
and specific requirements regarding information sharing and cooperation in order to improve patient-centred care, and secondly to map these specific and contextual requirements against available standards for information sharing.

My main research objectives are to study:
- Information and communication needs in patient-centred shared homecare; what information do different actors (health and social care professionals as well as patients and families) in patient-centred shared homecare need access to?
- Design and implementation of integrated applications to support shared homecare; how can the necessary information be made available to the different actors of patient-centred shared homecare?
- Standardized information models to support patient-centred shared homecare; do current standards meet the requirements elicited from patient-centred shared homecare?

To answer these questions, I have used different research strategies that are further described in section 3.1 Research process.
2 Background

There are some important areas closely related to my research. This chapter describes the organization of homecare of elderly in Sweden, the need for information sharing and cooperation in homecare as well as care planning as a tool for coordination in shared care. Integration and interoperability approaches as well as standards for information sharing in HIS and electronic records are presented to provide a background to the research performed in the OLD@HOME project. The project itself is briefly outlined in the latter part of this chapter.

2.1 Towards patient-centred shared homecare

In many western countries, homecare of elderly is shared between different healthcare provider organizations (Lind, Sundvall et al. 2002; Leichsenring 2004; Hedman, Johansson et al. 2007). Elderly patients often have complex and interrelated problems comprising physical, psychological and social health (Alaszewski, Billings et al. 2004). This complexity requires collaboration between and integration of health and social care. Elderly homecare consists of both healthcare services, namely provision of medical treatment by trained medical and nursing personnel, and home help (or social) services, such as domestic work and personal services. In Sweden, where the research presented in this thesis has been performed, homecare of elderly patients is shared between county councils, municipalities and private care providers (Hedman, Johansson et al. 2007; Petrakou 2007; Winge, Johansson et al. 2007).

Homecare of elderly therefore falls into the definition of shared care as an organizational principle where two or more healthcare providers jointly cooperate to provide healthcare services to a subject of care for a continuing health issue (EN13940-1 2007). To be effective, shared care requires structured coordination of medical activities. Clinicians must know what guidelines or protocols to follow. They must also trust each other’s actions and interventions (Branger, Duisterhout et al. 1997). When different providers are involved in a patient’s care without proper coordination, the care process may not be meaningfully integrated. A patient receiving care under such conditions may be subject to unjustified interventions or justified actions may not be performed. Communication is considered a vital aspect of shared
care from both a medical and a cost-effectiveness point of view (Branger, Duisterhout et al. 1997). Therefore, quality principles, such as **seamless care**, focusing on the timely and appropriate transfer of activity and information between healthcare providers, have been defined in relation to shared care (EN13940-1 2007). When shared care includes such quality principles, providing for example seamless and continuous care, we may refer to it as **integrated care**. The need for integrated care of elderly patients has been acknowledged in a number of studies (Alaszewski, Billings et al. 2004; Leichsenring 2004).

2.1.1 Patient-centred shared care

The term patient-centred care can be interpreted in different ways (Stewart 2001; Wagner, Bennett et al. 2005). To some it means a shift from a focus on disease to the patient’s feelings and experiences, integrating social and psychological factors to achieve a fuller understanding of the illness. The concept can also be used to focus on a shift in control over the relationship, communication and decision making from healthcare professionals to patients. Stewart states that being patient-centred actually means taking into account the patient’s desire for information and shared decision making, and responding appropriately (Stewart 2001).

Important as they are, these aspects focus only on the relationship between a patient and one care professional. When discussing shared care, I use the term patient-centred as meaning a **care model that allows all involved actors to have an integrated view of the patient care process**. In short, for shared care to be truly patient-centred it needs to be integrated. In this sense, a patient-centred HIS allows an overview of a patient’s care, irrespective of organizational boundaries. In contrast, an organization-centered HIS only allows a view of the care provided to a patient within one organization.

Integration of care providing organizations involved in shared care is however problematic. In shared homecare, collaboration is needed between healthcare professionals who rarely meet and face ongoing challenges in coordinating their work, since they belong to different organizations, distributed to different locations (Alaszewski, Billings et al. 2004; Bricon-Souf, Anceaux et al. 2005; Petrakou 2007; Winge, Johansson et al. 2007). Information and communication technology (ICT) have been suggested as means to improve cooperation and coordination in shared homecare (Andersson, Beck-Friis et al. 1999; Andersson, Hallberg et al. 2003; Bricon-Souf, Anceaux et al. 2005). Studies focusing on cooperation and coordination in shared care often focus on communication or information sharing between primary care and hospital care, as is indicated by the overview presented by Bodenheimer (Bodenheimer 2008). Bodenheimer refers to studies regarding cooperation between primary care physicians and a number of different healthcare providers, as well as between physicians and patients, but in-
cludes no studies regarding coordination between health and social care (Bodenheimer 2008). The area of information sharing and coordination between healthcare and social care is however achieving more attention and a number of studies focusing on collaborative processes in shared homecare have been published recently (Johansson 2005; Winge, Johansson et al. 2005; Petrakou 2007; Winge, Johansson et al. 2007). Unfortunately, few studies describe implemented ICT tools to support such cooperation and the effects of such ICT on integrated care.

2.2 Information sharing and cooperation in homecare

Coordination of care for chronically ill patients places large demands on the information-processing capacity of involved care professionals and the efficiency of communication with other care providers (Branger, Duisterhout et al. 1997). This is of course also true for care of elderly patients, who often suffer from chronic conditions. When care is provided by a single organization, for instance within a hospital or a clinic, coordination between healthcare workers is facilitated by frequent formal or informal meetings, as well as by a large number of exchanged documentation; for example medical records and laboratory results. In shared care, however, the team consists of distributed healthcare professionals, who rarely meet and have little access to shared documentation (Reed and Stanley 2003). Since care documentation is traditionally used as a communication medium between care providers (Andersson, Hallberg et al. 2003) the lack of shared documentation hinders cooperation in shared homecare. Providing ICT that enables sharing of documentation and information therefore has the potential to greatly improve cooperation in such shared care settings.

Different research fields approach issues relating to ICT tools for homecare of elderly. Koch presents a literature study of research on ICT in the homecare setting within the fields of medical informatics and biomedical engineering (Koch 2006). The study shows that a majority of research papers have a strong technical viewpoint supporting two dominant services; vital sign parameter measurement (Vidt, Bolen et al. 1991; Franktz 2003) and audio-video teleconsultations (Allen, Roman et al. 1996; Maglaveras, Koutkias et al. 2002; Demiris, Speedie et al. 2003). However, less focus has yet been given to the use of ICT to improve information access and communication for healthcare professionals, patients and relatives, in order to facilitate cooperation.

Involvement of patients and relatives in elderly homecare through access to patient-specific health information is also largely unaddressed. Research addressing patients and family carers in homecare of elderly is often focused on smart home applications (Doughty, Lewis et al. 2000; Tang and Venables
2.2.1 Care planning as a tool for coordination in shared care

Care planning is often discussed as a means to improve quality of care and provide structure to the care process (Reed and Stanley 2003; Voutilainen, Isola et al. 2004; Lee 2005). Descriptions of computerized care plans are often limited to two types of care plans; (1) discharge planning when patients are transferred from in-hospital to primary care (Reed and Stanley 2003), and (2) standard care plans for short term specialist care or chronic disease management (Ammenwerth, Kutscha et al. 2001; Lee, Yeh et al. 2002; Danko, Kennedy et al. 2003; Lee 2005). However, the complexity of many elderly
patients’ interrelated problems creates difficulties when using standardized care plans. Instead, tools that allow for shared care planning, providing access to planned interventions from different care provider organizations as well as self care interventions and active participation of patients and family carers, may have the potential to improve collaboration and overview of the care process in areas such as shared homecare of elderly patients.

From an informatics point of view, limited focus has been given to studies of information sharing between healthcare and social service organizations. To enable sharing of information, such as care plans, between different actors who use different HIS in their daily work, it is crucial to take important issues of interoperability into account.

2.3 Integration and interoperability

Having elaborated on the need to closely study the actual setting and organization into which ICT is to be introduced, and the importance of adapting technology to fit into that context, I will now discuss issues of interoperability and standardization.

As healthcare has evolved from being focused on a single meeting between a physician and a patient, to a complex inter-organizational network of specialties, care professions, researchers and administrators, so have the requirements for development of health information systems (HIS). Haux describes how early HIS were primarily intended to support healthcare professionals, mainly physicians, as well as administrative staff in hospitals (Haux 2006a). Yet today, there is increased realization that HIS need to include other professions as well as patients and their relatives. In addition, the use of data in HIS has shifted from almost exclusively being used for patient care and administrative purposes to also being used for secondary purposes such as public healthcare planning and clinical research (Haux, Ammenwerth et al. 2002). As the purposes and usage of HIS change, so do the needs for integration and interoperability. The increase in use of HIS also increases the number of specialized applications, and standards for integration and information sharing are required to enable information exchange between applications from different vendors.

Integration of information systems can be defined as the combination of diverse application entities into a relationship which functions as a whole (Saranummi, Piggott et al. 2005). In contrast, interoperability is a state which exists between two application entities when one application entity can accept data from the other and perform that task in an appropriate and satisfactory manner, without the need for extra operator intervention (Saranummi, Piggott et al. 2005). In short, HIS can be integrated to achieve interoperability. Depending on the way integration is designed and performed, different levels of interoperability (syntactic or semantic) can be achieved.
The purpose of integration is important and can span over a wide area of applications, posing different demands on the design of an integration architecture. The purposes for integration may include

- to support daily cooperation between care professionals,
- to support the transfer of patients between care provider organizations,
- to support secondary purposes such as public health planning and research, or
- to enable patient mobility on a larger scale, making information available on for example a national or international level.

Other important aspects that may affect the choice and design of integration architecture include; potential legacy systems that are to be integrated, their design and scope; and available resources for the implementation, including competences, finance and time. In addition, the specific criteria noted by Wozak et al in their study on architectures for shared electronic health records can be useful to consider when designing integration architectures. These criteria include; (1) Data organization, (2) Data retrieval and search functions, (3) Security, authorization and authentication, (4) Patient identification, and (5) Response time (Wozak, Ammenwerth et al. 2005).

Integration of HIS can be made locally between two systems. By creating a connection between these specific systems it is possible to exchange a particular amount of data or trigger predefined functionality. However, as different HIS are based on different information models and may use different terminologies this process is time-consuming, and needs to be repeated for each additional system with which interoperability is required. In response to this, standards are being developed to facilitate integration and interoperability of HIS. This involves both standardized structures for healthcare data, such as reference information models, and standardized content, in the form of for example conceptual models and terminologies.

2.3.1 Electronic records

Before describing current standards for information sharing, I would like to discuss one of the most important HIS used in healthcare; the electronic clinical record. There is today little consensus with respect to terms used to signify different types of electronic records (Coiera 2003; Waegemann 2003; Protti 2007). Terms such as Electronic Patient Record (EPR), Electronic Medical Record (EMR) and Computer-based Patient Record (CPR) are all used to represent clinical data of an individual. Electronic Health Record (EHR) is a term that is increasingly gaining ground. It is sometimes used to refer to computer-based clinical data of an individual that is available across multiple locations (Protti 2007). Elsewhere, this term is used as a visionary concept describing a fully interoperable and lifelong electronic record. It is sometimes difficult to make a distinction between such a visionary definition of the term EHR and other concepts that explicitly address an integrated
record solution, for example Virtual Health Record (VHR) (Forslund, Phillips et al. 1996; van der Linden, Talmon et al. 2002; Koch, Hägglund et al. 2004), Federated HealthCare Record (FHCR) (Hurlen, Skifjeld et al. 1998), and Shared Electronic Health Record (SEHR) (Wozak, Ammenwerth et al. 2005; Wozak 2007). In this thesis, I have therefore chosen to use the term EHR as a general concept representing an electronic record used by one or more care professions, but without distinguishing between integrated and non-integrated solutions.

I use the term VHR for representing an integrated health record. I define a VHR as a solution that provides users with an integrated view of information stored in different HIS, in different locations. Different actors require and consequently access different subsets of integrated information through their VHR view. Actors accessing this information range from health and social care providers, to patients and their relatives.

2.3.2 Standards for information sharing

Over the last two decades several standards have been developed to communicate parts of the electronic record for different purposes, such as transmissions of laboratory orders and results. In Europe and Australia, these efforts started as results from using EDIFACT (Electronic Data Interchange for Administration, Commerce and Transport), and further standardization work has been driven within CEN/TC251. In USA, standardization is to a large extent based on work performed within Health Level Seven (HL7), a non-profit, ANSI accredited Standards Developing Organization (www.hl7.org). HL7 version 2 has been widely implemented. The current version, HL7 version 3, encompasses the HL7 Reference Information Model (RIM) and the Clinical Document Architecture (CDA).

In addition, the industry initiative Integrating the Healthcare Enterprise (IHE) promotes the coordinated use of standards such as HL7 and DICOM in order to improve information sharing in healthcare (www.ihe.net). Initiatives such as these are important to evaluate the applicability of standards in real healthcare settings.

From a research perspective several important attempts have been made worldwide to solve the problems of EHR interoperability. The technologies of the Good European Health Record (GEHR) (Ingram 1995) and Synapses/Synex (Grimson, Berry et al. 1998; Hurlen, Skifjeld et al. 1998; Grimson, Stephens et al. 2001) projects (1992-1999) can be seen as the first mature approaches to reach interoperability through integration of EHRs.

These research projects have influenced the development of the European Standard for Electronic Health Record Communication EN13606, which has
also become an international standard (ISO/EN 13606)\(^1\) (ISO/EN 13606-1 2008) and openEHR (openEHR 2007), which will now be described in further detail.

ISO/EN 13606 and openEHR
The openEHR foundation (www.openEHR.org) is a non-profit open source organization bringing together an international community of people working towards realization of interoperable EHRs to support seamless and high quality patient care.

The openEHR architecture evolved from the GEHR project. Its main feature is a so-called two-level modeling approach, consisting of one level for information processing and another level for domain knowledge representation (Beale 2002; Bird, Goodchild et al. 2003). The methodology has been incorporated into ISO/EN 13606\(^2\).

The two-level modeling approach distinguishes a reference model (RM) to represent the generic properties of health record information, and archetypes (conforming to an archetype model). Archetypes are constraints of the underlying information model used to define patterns for the specific characteristics of the clinical data that represent the requirements of each particular profession, specialty or service. By using such an approach, the information and the knowledge level (represented by the archetypes) are clearly separated in a modular and scalable architecture (Eccher, Purin et al. 2006).

The RM defines the set of classes that form the generic building blocks of the EHR (ISO/EN 13606-1 2008). The main hierarchy components of the ISO/EN 13606 RM are presented in table 1.

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\(^1\) ISO 13606 is an international standard which is “materially identical to its European equivalent” (ISO/EN 13606-1 2008) (p. xxiii).

\(^2\) ISO/EN13606 Part 1 Reference Model (RM) is a subset of the RM specified by openEHR and the Archetype Model in ISO/EN13606 Part 2: Archetypes (ISO/EN 13606-2 2007) is equivalent to the one published by openEHR.
## Table 1: The main hierarchy components of the ISO/EN 13606 RM (adapted from (ISO/EN 13606-1 2008))

<table>
<thead>
<tr>
<th>EHR hierarchy component</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>EHR_EXTRACT</td>
<td>The top-level container of part or all of the EHR of a single subject of care, for communication between an EHR provider system and an EHR recipient. An EHR_EXTRACT contains EHR data as COMPOSITIONs, optionally organized by FOLDER hierarchy.</td>
</tr>
<tr>
<td>FOLDER</td>
<td>The high level organization within an EHR, dividing it into compartments relating to care provided for a single condition, by a clinical team or institution, or over a fixed time period such as an episode of care.</td>
</tr>
<tr>
<td>COMPOSITION</td>
<td>The set of information committed to one EHR by one agent, as a result of a single clinical encounter or record documentation session. COMPOSITIONs contain ENTRYs, optionally contained within a SECTION hierarchy.</td>
</tr>
<tr>
<td>SECTION</td>
<td>EHR data within a COMPOSITION that belongs under one clinical heading, usually reflecting the flow of information gathering during a clinical encounter, or structured for the benefit of future human readership.</td>
</tr>
<tr>
<td>ENTRY</td>
<td>The information recorded in an EHR as a result of one clinical action, one observation, one clinical interpretation, or an intention. This is also known as a clinical statement. ENTRYs contain ELEMENTS, optionally contained within a CLUSTER hierarchy.</td>
</tr>
<tr>
<td>CLUSTER</td>
<td>The means of organizing nested multi-part data structures such as time series, and to represent the columns of a table.</td>
</tr>
<tr>
<td>ELEMENT</td>
<td>The leaf node of the EHR hierarchy, containing a single data value.</td>
</tr>
</tbody>
</table>

The openEHR RM specifies some components further than ISO/EN 13606. One of the major differences between ISO/EN 13606 and openEHR is the latter’s specification of different subtypes of ENTRY (figure 1).
Archetypes describe the information structure of medical concepts, such as blood pressure, laboratory tests and diagnosis. They are authored by domain experts by means of an archetype editor and stored in an archetype repository. Repositories of clinical content models in the form of openEHR archetypes and templates have been established by the openEHR clinical community and the National Health Service – Connecting for Health (NHS CfH) projects (Sato, Arnett et al. 2007; NHS Clinical Models 2008). These models are intended to be shared and reused to support semantic interoperability between EHR systems.

**EN 13940 - ContSYS**

A conceptual model describes the main concepts of a domain and their relationships from a certain point of view (van Bemmel and Musen 1997). In order to support collaboration between different care providers, it is important to share a basic conceptual model. EN13940 System of concepts to support Continuity of care – part 1: Basic concepts (ContSYS) (EN13940-1 2007) is a system of concepts to support continuity of care by creating basic concepts that are common to all healthcare organizations. Continuity of care considers the management of health information in two different perspectives; (1) local management of information about the subject of care, at the site of care provision and (2) information interchange between healthcare professionals (EN13940-1 2007). The ContSYS standard seeks to identify and define those processes which relate to the continuity of care. It specifically addresses the need to share patient related information during the process of care.
2.3.3 Integration approaches

In addition to standardization of concept and information models different approaches to integration of HIS have been suggested. Grimson et al describes different integration approaches to enable a FHCRI or VHR (Grimson, Grimson et al. 2000). They make a distinction between message based integration, data warehousing and common architecture of HIS.

- **Message based integration** has been effective for solving basic communication problems between systems, by sending standard messages carrying data, and is used for sharing segments of an electronic health record. However, it does not provide technical means for seamless creation and transparent access to shared information (Grimson, Grimson et al. 2000; Tsiknakis, Katehakis et al. 2002).

- **Data warehousing** allows data from individual systems to be integrated and homogenized in a data warehouse. Since the data is integrated it is possible to use the data as the basis for an integrated health record. A drawback of this approach is that the data in the participating information systems is duplicated in the warehouse.

- **Common architecture** is defined as a third alternative (Grimson, Grimson et al. 2000). By reaching agreement on a common architecture for EHRs, including a common information model, and common service interfaces, it would be possible to seamlessly access patient data from different electronic record systems. However, this is yet to be achieved as it has proven difficult to reach agreement on the precise definition of a health record architecture. The architecture of an information system (IS) describes its fundamental organization, represented by its components and their relationship to each other/the environment, and by the principles guiding its design and evolution (IEEE Std 1471-2000 2000).

2.3.4 Architectural models

Architectures which have certain characteristics in common can be summarized in an *architectural style* (Wozak 2007). As healthcare organizational structures evolve into networks of centers, distributed geographically and with a high degree of diversity and heterogeneity, so does the need for *distributed information systems* that enable integration and sharing of information. Couloris et al describes two architectural styles of distributed systems; the **Client server model** and the **Peer-to-peer model** (Couloris, Dollimore et al. 2005).

- **Client-Server model**: in this architectural style specific services are provided by servers and consumed by clients. This architectural style is commonly used in telemedicine, and is often based on data stored in a central data repository (Wozak, Ammenwerth et al. 2005). Benefits of this approach are the high level of control gained by storing data in one place. Search functions can be directly carried out by the server system, aspects
of authorization, authentication and access control are far less complicated compared to distributed solutions, patient identification can be kept unique for the server system, and response time is mainly dependant on the load of the server system and the network connections. Wozak et al conclude that a client-server architecture is the best choice for integration where a single institution exchanges data with a clearly defined number of receivers in a directed communication flow due to its relatively low complexity (Wozak, Ammenwerth et al. 2005).

- **Peer-to-peer model**: in this architectural style all of the processes involved in a task interact cooperatively as peers without any distinction between client and server processes. While the client-server model offers a direct and relatively simple approach to the sharing of data and other resources, it scales poorly. The centralization of service provision and management implied by placing a service at a single address does not scale well beyond the capacity of the computer that hosts the service (Coulouris, Dollimore et al. 2005).

An architectural style that has received increasing attention is the service-oriented architecture (SOA). A SOA is an architecture built around a collection of services with well-defined interfaces. A system or application is designed and implemented as a set of interactions among these services (Lewis and Wrage 2004). From a technical viewpoint SOA is essentially a collection of software services that communicate with each other over a network to pass data or to coordinate some activity. Services can be implemented using different technologies and can encapsulate functionality and information from existing applications, thereby allowing the reuse of legacy systems (Mykkänen, Riekkinen et al. 2005).

The most common technique used to instantiate a service-oriented architecture is **web services**. Web services are software components or applications which interact with one another using Internet technologies based on eXtensible Mark-up Language (XML). They offer a platform-neutral interfacing and communication mechanism, have wide infrastructure support, and have significantly increased the interest in SOAs (Mykkänen, Riekkinen et al. 2005).

General architectural models as the ones described above can be applied to many different types of applications. In addition to these general models, architectural models that are specific to a particular application domain may also be used (Sommerville 2007, p. 261). The EN 12967 HISA (Health informatics – Service architecture) standard, is such a reference architectural model for HIS. HISA consists of three parts; Part 1 Enterprise viewpoint; Part 2 Information Viewpoint; and Part 3 Computational viewpoint. The architecture is based on a middleware independent from specific applications and capable of integrating common data and business logic and of making them available to diverse, multi-vendor applications through many types of deployment (EN 12967-1 2007).
The results presented in this thesis are derived from the action research project OLD@HOME (Koch, Hägglund et al. 2004; Koch, Hägglund et al. 2005). The main purpose of the three year-project was to provide a seamless and consistent information and communication flow within homecare of elderly patients through establishment of a virtual health record (VHR), which is further described in Paper III. Using mobile technology, such as tablet PCs and personal digital assistants (PDAs), the VHR allowed for mobile information access and expanded provision of documentation to homecare staff at the point of care (Koch, Hägglund et al. 2004). The project focused on care of elderly patients still living in private homes, and it involved real users during the entire system development and deployment process.

Geographically, the project was located to the municipality of Hudiksvall, within the County Council of Gävleborg, in Sweden. Hudiksvall is a mainly non-urban, remote region. It has a population of about 37 000 inhabitants of which about 5.5 percent are aged over 80. This reflects the Swedish average of 5.2 percent of the population being elderly citizens (Swedish Institute 2007).

The region had an established fiber-optic network infrastructure connecting all test site locations. These locations were two primary care centres, the elderly patients’ private homes and one nursing home for the elderly, from where homecare of the elderly was coordinated. At the nursing home and in some of the private homes, WLAN hotspots were installed. All WLANs were configured for maximum security.

2.4.1 Participants

Five groups of participants in shared homecare of elderly were involved. These were:

1. three general practitioners (GPs), whereof one was involved in development of the VHR;
2. four district nurses (DNs), whereof two were involved in development of the VHR;
3. fourteen assistant nurses (ANs) working with home help service (HHS), whereof three were involved in development of the VHR;
4. two patients receiving homecare; and
5. four relatives of patients in the homecare area.

In addition, other stakeholders such as buyers/owners, developers/designers and operational services were involved to create a team approach according to a recommendation of a minimum set of stakeholders (IEEE Std 1471-2000 2000). All stakeholder groups were invited to initially set up common goals for the project. Throughout the project life cycle they continued to validate the conformity towards those goals (Moström, Hägglund et al. 2006).
Multi-disciplinary working groups were formed and engaged from the project start-up and throughout the development process. In addition to the user-focused groups, a system development/technical working group and an evaluation working group were also established. The technical group handled development, operational and technical services and consisted of staff from the industrial partners; XLEN'T technology AB, Bergsjo Data AB and ProfDoc AB as well as staff from the ICT departments at the involved care provider organizations. Health Informatics and Usability (HI-U) researchers worked within all groups as team managers mediating between system developers and clinical end-users (Scandurra, Hägglund et al. 2008b). The evaluation group contained domain experts and researchers from caring sciences at Uppsala University and University of Gävle.
3 Methods and materials

The focus of this thesis is the study of information needs in patient-centred shared homecare, and the exploration of how these needs can be fulfilled through integrated ICT. Before describing my research process and methods, I would like to describe the relationship between my research questions and the four papers presenting the results of my research. Figure 2 gives an overview of this relationship.

The first paper is a methodological paper, describing how scenarios can be used to capture context dependent needs for information sharing and collaboration in homecare. In Paper II, information that needs to be shared at intersection points between different actors in homecare today is identified.
The scenario-method described in Paper I was used to reach these results. Moreover, Paper II further suggests that gathering this information in *shared information objects* can be a means to support cooperation and a patient-centred care process in shared homecare via the use of ICT as an information sharing tool. In Paper III, I present the integration architecture and applications of a virtual health record (VHR) designed to meet the needs of patient-centred shared homecare of elderly. Finally, in Paper IV, I compare one of the shared information objects, namely the shared care plan model, with standardized models, namely ContSYS and openEHR RM.

In order to achieve these results I have used different research methods and system development methods. I will now continue to describe these methods in more detail.

### 3.1 Research process

Oates describes the research process as consisting of the following components: personal experiences and motivation, literature review, research question, conceptual framework, strategies, data generation methods and quantitative and/or qualitative data analysis (Oates 2006). Figure 3 shows how my own research process fits into this model.

![Figure 3: Model of the research process adapted from (Oates 2006), with my personal research process indicated.](image-url)
My motivation, research questions and conceptual framework have already been described. Data generation methods and data analysis will be described as part of the system development process used. When necessary, further description will be included in the summary of each paper. Before doing so, I would however like to elaborate on the research strategies I have used to meet my research objectives.

3.1.1 Research strategies

I have chosen to combine three different research strategies to cover the area addressed by my research objectives: action research, case study, and design and creation.

**Action research**

Action research is an important foundation for my research process. It is an approach that encourages researchers to experiment through action and to reflect on the effects of their intervention and the implication of their theories (Avison, Lau et al. 1999; Oates 2006). In the early days of action research, Lewin stated expressively that *if you want to know how things really are, just try to change them* (Lewin 1958). I believe this statement to still hold great truth. Lewin’s position is one of the reasons why I was not content to study the area of shared homecare only from the outside, but instead chose to develop and deploy ICT in a real life clinical setting. By using action research I hoped to affect the traditional ways of working and cooperating. When using an action research approach, the researcher faces difficulties in determining cause and effect. Research generalization is also a challenge. Nevertheless, at this stage I consider benefits of action research to outweigh such problems.

Action research is characterized by concentration on practical issues, an iterative cycle of plan-act-reflect, an emphasis on change, collaboration with practitioners, and use of multiple data generation methods (Oates 2006). The research presented in this thesis has had a strong focus on solving current, real life problems (coordination and information sharing) in a specific setting (shared homecare of elderly). An iterative cycle has been followed both in the research process and the system development process. The introduction of new designs and suggestions occurred right through the processes. This was married with ongoing analysis, reflection and ultimately the reintroduction of new suggestions. The emphasis on change was present throughout the research project, envisioning better ways of cooperating and communicating, while introducing new tools to enable improvement of these processes. Collaboration with practitioners has been an influential part of the work.

In addition, the outcomes of action research can be related to both research and action (Oates 2006). In this thesis, focus is on research results, but I will return to this distinction and comment on some action results in chapter 6, *Conclusions*. In short, I have used an action research strategy as
the overall framework for my research. I have however included other research strategies, and this enabled me to answer specific research questions.

**Case study**

One of my research objectives is to study information and communication needs in shared homecare. This part of my research involved providing a rich, detailed analysis of current information use and communication between different actors in shared homecare of elderly. To meet this objective, I chose to use a case study strategy.

According to Oates, a case study is characterized by focus on depth rather than breadth. A case study takes place in a natural setting, has a holistic perspective and makes use of multiple sources and methods (Oates 2006). These are all characteristics of the case study presented in Paper II. As part of an action research approach, the case study presented in Paper II had a dual purpose; (1) it aimed to both give an in-depth description of information sharing and cooperation in shared homecare, and (2) it served as a starting point for change, providing requirements for the design of ICT to improve information sharing and communication.

**Design and creation**

Important results of the research presented in this thesis are new artefacts, in this case ICT products. Oates refers to research which has the purpose to develop new artefacts as having a design and creation strategy (Oates 2006). New artefacts can include models and methods. New artefacts can also include working systems (instantiations) which demonstrate how suggested models and methods can be implemented using ICT.

My research objectives include the design of ICT to support information sharing and cooperation in homecare of elderly. Given this goal, a design and creation strategy is part of my research methodology. Notwithstanding this goal, a working system such as the VHR presented in Paper III is not the only artefact that has been developed as part of this research. Paper I presents a method for capturing communication and information needs in cooperative work and Paper IV describes developed models and their mapping against standardized models.

In my research, the design and creation strategy also constitutes an important part of the overall action research approach. Research participants were involved throughout the design of the VHR. Moreover, the deployment of the VHR was the driving factor in the action research goal to directly improve the current information sharing and cooperation between different actors involved in shared homecare of elderly.
3.2 A user-centred design process

In order to ensure that developed ICT meets the necessary local requirements, it is important to obtain a deep understanding of user needs and requirements, as well as the context into which a HIS is to be introduced. The ISO 13407 standard “Human-centred design processes for interactive systems” advocates active involvement of users to reach a clear understanding of users needs and context requirements. Appropriate allocation of functions between users and technology, iteration of design solutions, and multi-disciplinary design teams are suggested (ISO 13407 1999). However, there are obviously different methods to reach the results desired in ISO 13407. The OLD@HOME project used methods based on, for example, User-Centred Systems Design (UCSD) (Göransson 2004) and Participatory Design (Bødker and Iversen 2002). Both these approaches focus on usability throughout the development process, and indeed throughout the entire system life cycle (Gulliksen, Göransson et al. 2003).

In application development for healthcare, most approaches still focus on the individual healthcare professional, modeling only his/her decision making processes (Aarts, Peel et al. 1998; Berg, Langenberg et al. 1998; Berg 1999; Breder and McNair 2000; Beuscart-Zephir, Anceaux et al. 2001; Breder and McNair 2001; Kaplan 2001; Kinzie, Cohn et al. 2002; Kaplan, Farzanfar et al. 2003). The socio-technical approach (Berg 1999; Berg and Toussaint 2003) and computer supported cooperative work (CSCW) (Bannon and Schmidt 1989; Crabtree 2000; Hardstone, Hartswood et al. 2004), differ from more traditional work views as they emphasize the need to address cooperative work processes rather than discrete tasks for individuals (Berg 1998). However, practical methods for gaining insight into the work practices of professionals are still often limited to interviews, sometimes extended to observations and sketching exercises, and these methods rarely give the end-users opportunity to reflect on their cooperative work.

It is also crucial to translate the results of a work analysis into the actual design and development processes. There is often a gap between work analysis and technical specification. This gap may be hard to bridge, sometimes resulting in loss of valuable insights reached in the analytical steps. Thus, there is a need for procedures that bring an understanding of practice into specification design (Miettinen and Hasu 2002; Andersson, Hallberg et al. 2003). The methodological review by Johnson et al. advocates a variety of user-centered methods to conduct the analyses needed, with each method providing different but necessary components in order to design an initial prototype (Johnson, Johnson et al. 2005). This viewpoint is encouraged by Kaplan, proposing methodological pluralism to increase understanding of many influences concerning development and deployment (Kaplan 2001).

One of the OLD@HOME project’s objectives was the design and application of a detailed, practical method for capturing user needs for different
actors, in different usage situations and environments in order to support integrated and patient-centred care. The method was also designed to support the transfer of user needs into technical requirements specifications. This resulted in the Multi-disciplinary Thematic Seminar (MdTS) method (Scandurra 2008; Scandurra, Hägglund et al. 2008b). The method is not described in detail in my papers however, as the method was used extensively as a tool to obtain my results, a short description is given here.

3.2.1 Multi-disciplinary Thematic Seminar Method

The MdTS method ensures that the requirements of all actors involved in collaborative processes are elicited. It focuses on important intersection points between different actors and provides a holistic view of the entire collaborative process, as well as detailed descriptions of requirements in different situations. MdTS consists of a series of twelve thematic seminars (figure 4).

![Thematic Seminar Series Diagram](Image)

Figure 4: Thematic seminar series performed in multi-disciplinary working groups (Scandurra 2008).

Specific data gathering and analysis methods used as part of the MdTS method to achieve the results presented in this thesis are presented below.

**Participatory observations and interviews** were used to obtain insight into the context of shared homecare. The HI-U specialists spent a total of 17 days of field observations using a master-apprentice or contextual design method (Lave and Wenger 1991; Beyer and Holtzblatt 1998; Beyer and Holtzblatt May 1995). During field observations, these HI-U specialists followed the full-time work schedules of the care professionals, including
morning, afternoon and evening shifts. The observations included approximately three hours of in-field observations per shift. The observations were participatory in the sense that the HI-U specialist accompanied the health and social care professionals, actively participating in their daily work and acting as apprentices being introduced to the work. There was ongoing dialogue between the HI-U specialists and the health and social care professionals, including frequent questions and clarifications. The HI-U specialists also interviewed all participants to incorporate non-observable aspects of work practices. In addition to participant interviews, interviews were also held with one manager of home help service, one manager of primary care and one social care administrator.

An **inventory of current documentation and HIS** used in homecare was also performed to complement the insights from observations and interviews. Copies, photos, or descriptions of current homecare documents, both paper-based and computerized, were studied and categorized according to the kind of information they contained, such as administrative, patient-specific, health related, social care or information to facilitate planning. All documents were also categorized according to by whom, when and why they were required. Accessibility and purpose of each document were discussed in working groups.

Iterative **inter- and intra-professional seminars in interdisciplinary working groups** were held to analyse the intersection points between different actors in more detail (Scandurra, Hägglund et al. 2008a). Figure 4 shows the themes of twelve seminars that cover the multi-disciplinary work. The chosen topics covered a range of current and future work practices, incorporating exercises to bring out both holistic and detailed information. The first six seminars were focused on knowledge gathering with respect to the general homecare work processes (that is, gaining holistic information), while the final six seminars analyzed the results in detail. The complete seminar series aimed to encompass the necessary knowledge of current work situations, as well as visions of future work and new work practices, in shared care for development of HIS.

**Scenarios** were used as an important tool to describe current processes and identify when and why information exchange is needed between different actors. Information needs of healthcare professionals were discussed with focus on improving collaboration between different professions, as well as within the professional group. The information needs of elderly and their relatives were analysed from two perspectives: (1) identify information that would improve their sense of involvement and control; and (2) identify information that was available in current HIS and investigate how this information could be made available to patients and relatives without causing additional work for healthcare professionals.

The MdTS method was specifically developed for cooperative work. Application of the MdTS method requires working groups containing
Separate seminars were held with healthcare professionals and patients/relatives over a period of six months. Some seminars involved only one group of actors, whereas other seminars involved several or all groups, in order to capture both the needs of each separate group and the intricate details of intersection points where different actors meet. Seminars with the healthcare professionals were held approximately every two weeks (Scandurra, Hägglund et al. 2008b), while patients and relatives met approximately once a month.

Meetings and interviews were recorded and notes were taken. Notes were also taken during participatory observations. Gathered materials were examined repeatedly by the researchers, and important issues were categorized into themes using content analysis (Graneheim and Lundman 2004).

Sketching, future work scenarios and different level (both paper-based and computerized) prototypes of ICT to support collaboration and sharing of information were further used during the seminar work to envision suggested shared information objects. In an iterative process suggestions made by the HI-U specialists based on the analysis of gathered materials were revised and validated by involved care professionals and patients/relatives.

The transition of user needs to a system specification was facilitated by iteratively refined prototypes that were validated by the users in parallel with development of scenarios and use cases (Bittner and Spence 2002). The use case work was performed by the HI-U specialists as part of the system specification. The parts of the MdTS method involving scenarios and use cases are described in Paper I.

3.2.2 Integration approach

The major goal of the VHR was to integrate existing information assets, currently isolated in separate, organization-centred HISs, and to make these available to health and social care professionals as well as patients and relatives. In relation to the VHR, the organization-centred systems can be referred to as feeder systems. Sommerville states that large software systems always can be decomposed into sub-systems that provide some related set of services. He further notes that the initial design process of identifying these sub-systems and establishing a framework for sub-system control and communication is referred to as architectural design (Sommerville 2007, p. 242).

When designing the VHR, a key issue was the integration of information from different feeder systems, as well as the availability of information for end-users through different types of application or views. Therefore, the design of the VHR included specification of an integration architecture, which is presented in Paper III. The particular style and structure chosen for a sys-
tem may depend on non-functional requirements (Sommerville 2007). Important non-functional requirements revealed by the MdTS method that impacted on the architectural design of the OLD@HOME VHR were: need for mobile applications; need for both online and offline access to shared information; and need for access to heterogeneous information in feeder systems.

**Mobile applications** – mobile applications were required as the VHR was to be used in a homecare setting. Different user groups had different needs with respect to hardware; therefore, different solutions were developed for use on laptops/tabletPCs, or handheld devices.

**Online and offline access to shared information** – both online and offline applications were requested. In the OLD@HOME project, most locations where the VHR applications were to be used were connected to a fiber-optic network. This provided a fast and reliable connection. To allow wireless Internet connection, wireless hotspots were also installed in some patients’ homes. Online applications were used in patients’ homes and other locations where reliable Internet connection was available. Offline applications were however developed for handheld devices, as the transmission capacity through GPRS was insufficient for online access to the VHR. Moreover, the HHS often wanted to access information while walking between patients’ homes, or just before entering a patient’s home where no broadband connectivity was available. This influenced the choice of using a centralized data repository, a mediator database, to which information from feeder systems was published. The SQL Server CE databases used locally on the handheld devices could then be synchronized against this mediator database, allowing for offline access to information on handheld devices.

**Access to heterogeneous information in feeder systems** – an OLD@HOME project goal was to access information from current HISs. This information was stored in heterogeneous formats. In order to handle the heterogeneity, both with respect to information models and technical platforms, web-services were used to access information.

In addition, some functional requirements also influenced the choice of using a **mediator database**. The MdTS scenarios revealed functionality that required the documentation and access to information that was not available in any of the feeder systems. In order to provide such functionality, it was necessary to include a mediator database for storage. In a long-term perspective such functionality should ideally be implemented in the appropriate feeder system.

In short, a **hybrid architectural approach** (Wozak 2007) was chosen, making use of specific central services in a distributed environment. This solution is described in more detail in Paper III.

**Platform for the VHR**

Technically, the platform for implementation of the integration architecture was Microsoft .NET, using Biz-Talk Server 2004 for information handling, SQL Server 2000 and SQL Server CE 2.0 for data storage, SharePoint Portal
Server for handling of web-portals, and XML as format for data exchange. Microsoft Visual Studio .NET and .NET Compact Framework were used as developer platforms. Microsoft Authorization Manager (AZMAN) was used for handling of access rights. An external firewall was used to fully secure all communications and to prevent unauthorized remote access to central server systems.

3.2.3 Evaluations of the VHR

An important part of all design and creation research is evaluation of the developed artefacts (Oates 2006). Depending on their purpose and place in the development process, evaluations can be either formative (constructive) or summative (Hartson, Andre et al. 2001). A formative or constructive evaluation is made during the actual design process, with the purpose of finding problems to be dealt with and to control a dynamically changing development process. A summative evaluation is made after the development is finished, to assess the final results.

The OLD@HOME project applied both formative and summative evaluations. Multi-disciplinary working groups gradually developed and assessed new versions of VHR prototypes. As part of the OLD@HOME project, the final VHR system was used for five months by the three care professional groups who were regularly involved in the treatment of 18 elderly patients within one homecare district. Informed consent from these patients was acquired. During this test period, the three care professional groups included 14 ANs from the HHS, two DNs, and two GPs. Evaluations of the VHR are described further in (Koch, Hägglund et al. 2005; Scandurra, Hägglund et al. 2006b; Scandurra, Hägglund et al. 2008c; Engström, Scandurra et al. 2009). The major part of these evaluations were presented in Isabella Scandurra’s PhD thesis (Scandurra 2008) however, as the evaluations provide important validation of the developed system, a summary of their results will given in section 4.3.3 Results of the VHR evaluations.

3.2.4 Concept modeling and information modeling

The MdTS method identifies information that needs to be shared. This information was grouped into shared information objects. These objects formed the basis for concept and information modeling in the OLD@HOME project, using unified modeling language (UML). These models then formed the basis for the design and implementation of the XML schema used for mapping information from different feeder systems into a common format (see 4.3.1 Integration architecture).

Concept modeling is used to describe a concept system within a subject field. This description can clarify the relationships between the concepts, and illustrate some of their definitions. Information modeling has the purpose of
organizing the information objects, each one representing knowledge about a concept. In an information model, however there is also additional information pertaining to the properties of the information objects, shown as attributes to the objects, and operations describing behavior of the objects.

Standardized representation of shared information objects

The final study presented in this thesis (Paper IV), is a mapping of OLD@HOME models and requirements against standardized concept models and EHR information models. We chose to use ContSYS and ISO/EN 13606, as they are accepted European standards and should be implemented in European healthcare settings. However, after initial investigation, it was discovered that the openEHR RM is more detailed in some areas, and therefore further improved our research. As the ISO/EN 13606 and openEHR are so closely matched, we decided to use the openEHR RM instead. In addition, archetypes that are currently available are almost exclusively modeled according to the openEHR RM.

The mapping of OLD@HOME models against standardized models had a twofold purpose: (1) to verify the OLD@HOME models compliance with standardized models and; (2) to explore whether the standardized models meet the requirements of shared information objects as identified in the OLD@HOME case.

In part 1 of ISO13606 a comparison between ISO/EN 13606-1 and ContSYS is made (ISO/EN 13606-1 2008). In this analysis it is stated that since most of the ContSYS constructs relate to clinical information, they will be represented as specific archetypes rather than as classes and attributes in ISO/EN 13606 RM (ISO/EN 13606-1 2008). However, some fundamental concepts are deemed to have links to the reference model. For example, a care plan is suggested to be represented as a COMPOSITION and/or a set of ENTRYs, with a LINK to a programme of care COMPOSITION, whereas activities bundles will be a set of COMPOSITIONs and/or ENTRYs within an EHR that have a LINK to a particular care plan (ISO/EN 13606-1 2008). We took these suggestions into consideration when further transforming the OLD@HOME domain concepts to the openEHR RM.

Creating archetypes

ISO/EN 13606 defines archetypes as “effectively pre-coordinated combinations of named RECORD_COMPONENT hierarchies that are agreed within a community in order to ensure semantic interoperability, data consistency and data quality” (ISO/EN 13606-2 2007). A major benefit of using archetypes is considered to be their reusability.

The recommended approach when designing archetypes is one including a maximum data set. The designers should consider all potential uses of a certain archetype, and include all the information that might be needed in different contexts. Blood pressure is often used as an example. An archetype
representing the concept should include all attributes needed by a specialist investigating severe hypertension, whereas the information needed for a simple blood pressure reading in primary care requires significantly less data. When applications are developed for different contexts, templates can be used to delimit the attributes available in that specific context. The underlying archetype will however remain the same. This enables sharing of information between different healthcare settings.

As the majority of archetypes available in archetype repositories are based on the openEHR standard, we chose to model our archetypes according to openEHR. The Ocean Informatics Archetype editor was used. Before creation of archetypes was initiated, known archetype repositories\(^3\) were explored in search of available archetypes that could be reused in the shared care plan. Archetypes that are published in these repositories have undergone extensive peer-review and are a valuable source for all archetype developers (Garde, Hovenga et al. 2007).

It has been suggested that the openEHR archetype approach empowers healthcare professionals to define and alter the accurate knowledge and information they need in the granularity they need (Garde, Knaup et al. 2007). In the study described in Paper IV, domain experts were not actively involved in the actual archetype modeling. Instead, the creation of archetypes was based on available models from the OLD@HOME case.

\(^3\) The openEHR archetype repository; http://www.openehr.org/svn/knowledge/archetypes/dev/html/en/ArchetypeMap.html
4 Summary of papers

The work presented in this thesis is based on four papers, and before going into details of each paper, I would like to give an overview of their internal relationships (figure 5).

![Diagram of paper relationships]

In short, there is a straight line from Paper I (method: information needs acquisition), through Paper II (results: requirements) to Paper III (results: implementation). Paper IV places the results from Paper II and III in the context of standardized concept models and information models. The results presented in Paper IV are a mapping of results from Paper II against current standards.

4.1 Scenarios to capture cooperative work processes (Paper I)

Paper I describes a scenario-based method whereby cooperative work processes and information needs were captured. The scenario-method was developed and used as part of the MdTS method in the OLD@HOME project. This method was an important tool in unveiling the results presented in Paper II, and also in translating these requirements into the system development process. These steps resulted in the implemented system presented in Paper III.
A wide range of scenario usage has been proposed in HCI research. Scenarios can be used for analyzing user tasks, envisioning future work, mock up and prototyping, evaluation of an implemented system, as well as for eliciting user requirements, deriving specifications and analyzing and describing current system usage (Go and Carroll 2004). Scenarios can also been seen as ranging from abstract descriptions of needs and environments to detailed technical specifications for implementation of a system. Use cases are an example of the latter type of scenario, as set out in figure 6 below.

Bødker discusses scenarios as a basis for overall design and for technical implementation. These scenarios are applied as a means of cooperation within the design teams and across professional boundaries, with some examples being between users and designers or between usability people and technical designers and implementers (Bødker 2000). It is in this role that I see the use of scenarios in my work. More specifically, user-centred scenario building was applied for the following reasons;

- **To concretize and illustrate the usage situation.** The goal was to describe and analyze the different professions’ current work situations, with or without ICT, and to envision how these work situations could be supported by ICT in the future. Cooperative aspects, including communication and information sharing within the care providing team, were given special focus.

- **To support inter-professional communication.** The scenarios served as an important means to improve communication and understanding between both developers and end-users, and between different end-user groups. Many healthcare professionals are focused only on their role in the healthcare process and have little understanding of other professions’ work. Access to scenario-descriptions from different perspectives gave new insights to many care professionals.

Figure 6: Range of scenarios in design, adapted from (Benyon and Macaulay 2002), also indicating where on this scale our work is located.
• To **support the transition from work analysis to system specifications.** There is often a gap between work analysis and technical specification. This sometimes results in loss of valuable knowledge gained in the analytical steps. There is a need for procedures that bring an understanding of practice into specification design (Miettinen and Hasu 2002; Andersson, Hallberg et al. 2003). I further propose that scenarios can be used as a tool bringing transparency into such procedures.

I will now continue by describing my proposed use of scenarios for these purposes. I will draw on practical scenario-method examples from the OLD@HOME project.

### 4.1.1 From analysis to application

Again, the main methodological framework in which scenario building is applied, is the MdTS method (Scandurra, Hägglund et al. 2008b). In order to explore the situations that are represented as scenarios, a number of methods are used;

- **Participatory observations and interviews** are used to obtain insight into the context of the collaborative work. Interviews are used to incorporate non-observable aspects of work practices.

- An **inventory of current documentation and HIS** used in the studied context is also taken. This complements the insight from observations and interviews. Copies, photos, or descriptions of current documents, both paper-based and computerized, are studied and categorized according to which type of information they contain, and by whom, when and why they are required. Accessibility and purpose of each document are also discussed.

- **Iterative inter- and intra-professional seminars** in interdisciplinary working groups are held to analyse the intersection points between different actors in more detail (Scandurra, Hägglund et al. 2008a).

Work situations are discussed and described, in what may be compared to the **user stories** in figure 4. Although useful for identifying problem situations and as triggers for discussion within the working groups, such descriptions are often very general and not especially useful in the detailed design of a system. To address this, a structure is needed to ensure the descriptions of work situations are specific enough to be useful. For this purpose, the documentation template presented in table 2 was designed. The template gives special attention to cooperative aspects of the activities and differences between current and future work. The scenarios include general descriptions of information needs, communication flows, need for documentation facilities and tools for planning.
Table 2: Documentation template of the work scenarios

<table>
<thead>
<tr>
<th>Activity</th>
<th>Cooperation</th>
<th>Today</th>
<th>Future</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activity 1</td>
<td>With whom do you cooperate/communicate?</td>
<td>How do you cooperate? Communication, transfer of information etc</td>
<td>Could/should this change in the future? How should it change?</td>
</tr>
<tr>
<td>Short description</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activity 2…</td>
<td>…</td>
<td>…</td>
<td>…</td>
</tr>
</tbody>
</table>

Each scenario describes one work situation, with each work situation further broken down into several different activities. A context description of each work situation is given, providing background information on when and why a certain work situation occurs. The activities are given short, but reasonably detailed descriptions. While working on these descriptions in the working groups, questions may arise that require further observations or interviews. This new information may ultimately lead to changes in the list of work situations.

In order to focus on the complex communication and cooperation taking place in shared homecare, the analysis continues by focusing on cooperative aspects of each activity. A list of actors involved in each activity is created, as well as a list of currently used communication tools. The necessary healthcare communication is analyzed by asking questions about the type and context of the communication, for example “when?”,” “where?”,” “with whom?”,” and “why?”.

After having fully explored all current work situations focus is transferred to future work scenarios. The prerequisites, boundaries, and limitations to concretize staff expectations of future work are analyzed. The analysis also considers which parts in the organization need change, and a judgment of how difficult or complex the change management process would be to achieve. The working groups prioritize scenarios and detailed descriptions of selected work situations are documented and iteratively improved. Sketches and prototypes are used to visualize future work scenarios. While discussing and testing sketches and prototypes participants reflect on present and future work practices and iteratively evaluate expected effects in advance. For instance, ways that ICT tools can improve efficiency are discussed. Moreover, participants formulate their own goals for their future work.

The work situations, as described in the work scenarios, are however still too vague to be truly useful for developers in charge of implementing an ICT-system. Therefore, the scenarios are transformed by HI-U specialists into conventional use cases (Bittner and Spence 2002). This process includes prioritizing the work scenarios, or rather, the activities they consist of, and deciding
which ones should be supported by the proposed ICT. This results in a specification of system functionality which takes different professions’ specific requirements into consideration. This also allows the different professions’ specific requirements to have a direct impact on application design and implementation before any coding is performed. The new system specifications are then validated by participating groups and agreed upon by all stakeholders.

4.1.2 Scenarios capturing cooperative aspects in OLD@HOME

To clarify how working with scenarios assisted in capturing cooperative aspects of shared care, as well as the impact this had on the implemented applications, Paper I presents one of the HHS’s work situations tracing the development process from a scenario description to implemented application. The scenario, *Change in medication*, is presented in table 3.

<table>
<thead>
<tr>
<th>Scenario: Change in medication</th>
</tr>
</thead>
<tbody>
<tr>
<td>A new medication has been assigned by the GP, or changes have been made in current medication. DN informs the HHS about this change and gives instructions.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Activity</th>
<th>Cooperation</th>
<th>Today</th>
<th>Future</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Receive instructions</strong></td>
<td>DN – HHS Indirect with GP (via DN)</td>
<td>Verbal;</td>
<td>Written, ICT;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Face-to-face</td>
<td>• Automatic message</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Telephone</td>
<td>Verbal;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Written, paper;</td>
<td>• Face-to-face</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• note left in</td>
<td>• Telephone</td>
</tr>
<tr>
<td></td>
<td></td>
<td>home with</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>instructions</td>
<td></td>
</tr>
<tr>
<td><strong>Document</strong></td>
<td>Within HHS-team</td>
<td>Written, paper</td>
<td>Written, ICT;</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Message sent to all team</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>members</td>
</tr>
</tbody>
</table>

The scenario captures the cooperation and communication taking place with other healthcare professionals in a specific work situation; both within the HHS-team and more broadly. It also specifies different tools, or means of communication, which are available today. Finally, potential solutions for the future are suggested on a high-level.
Future Work Scenario: Change in medication

Goal: To be informed of changes made in a patient’s medication, complete with additional instructions from the DN. This information should reach the entire team.

Receive change in medication
When the GP changes the medication the HHS receive an instant message in their handheld devices.

Complementary information
If further information (such as specific instructions for treatment) is required, the DN adds this.

Dissemination
Updated information (including added instructions from the DN) reaches the entire HHS team instantly and is re-accessible later.

Future aspects of each work situation were described by the care professionals in terms of goals. Future work scenarios with suggested solutions for achieving these goals were then designed in detail by the HI-U specialists and verified by the care professionals. In Table 4 the future work scenario for Change in medication is provided.

One of the major benefits of the scenario building was that the scenarios formed a basis for discussion during the inter-professional work. In several cases, comparing the DN’s scenario for a certain work situation with the HHS’ scenario for the same situation showed that their views on the care process differed and that they had limited insight into each other’s work.

Transformation of scenarios into use cases resulted in a specification of system functionality transparent to different professions’ specific needs. For the Change in medication scenario, the necessary functionality was: access/read prescription list which all participating professions would be able to do; add new prescription which was only available to DN and GP; and add complimentary information which was available to DN only.

In addition to the work scenarios, results from sketching and prototyping were useful in the process of creating detailed use cases. Different design solutions were suggested in paper prototypes. These were then discussed and amended/rejected by the working groups. Accordingly, already validated design decisions in the form of prototypes or sketches were easily incorporated into the use case descriptions, making them highly detailed. An example of a use case description related to the future work scenario Change in medication is presented in Figure 7, Add complimentary information.
As the use cases focus on the application to be developed, the scenarios were brought to a detailed level. This scenario-information was also useful in other parts of the design and implementation process, including information modeling and database design. In combination, the scenarios and the use cases were mutually understandable and thus bridged the gap between users and developers.

4.1.3 Conclusions

In conclusion, a method using structured scenarios to describe healthcare professionals’ current work situations, as well as their expectations, needs and requirements for the future made it possible to create the basis for a validated design that could be understood by both developers and users. Working with scenarios in both intra- and inter-care professional working groups created insight into cooperative work processes and built understanding between different clinical groups. By iteratively transforming the scenarios into more technical use cases, the gap between work analysis and system design...
was bridged. This simultaneously created transparency and traceability in the development process.

The scenario method was a useful tool in the analysis of information sharing, communication and cooperation in current shared homecare. It was also useful for suggestion and design of ICT to support these processes. A description of these results from the OLD@HOME case is presented in Paper II.

4.2 Information needs in homecare of elderly (Paper II)

One of my research objectives was to study information and communication needs in shared homecare, and a case study strategy was used to obtain the results presented in Paper II. The objective was however not merely to describe this context, but also to provide requirements for the design and development of ICT to meet these needs. In addition to traditional case study methods for data gathering, such as interviews and observations, the MdTS method, described in section 3.2.1 The Multi-disciplinary Thematic Seminar method, and scenario method, described in Paper I, were also used. This work aimed to identify intersection points where different actors involved in homecare of elderly interact, and to analyze their need of information from various sources. Different actors involved in homecare of elderly include healthcare and social care professionals, as well as patients and relatives. Finally, the case study also aimed to suggest how this information could be made available and communicated.

4.2.1 The context of elderly homecare

The OLD@HOME case study provided a rich description of the context of elderly homecare in Sweden today, including the different types of HIS used in the study setting. I will here give a more detailed summary of the elderly homecare context.

Many elderly receive care from many different care providers. Due to cooperation difficulties between the care providers, the patients are often the only ones expected to have an overview of their care. Relatives of elderly patients often play an important part in their lives. As elderly patients are often forgetful, their relatives, especially if living at a distance, contact their care providers, often the HHS, to keep informed.

Elderly patients receiving homecare are often visited daily by HHS staff, although this depends on amount and level of granted services. HHS staff provide both social care (for example help with personal hygiene, preparing meals and cleaning) and basic healthcare services (tasks delegated by the DN or physiotherapists). At the time of the study the HHS team used only paper-based information systems;
• **Patient Binder** – each patient’s personal binder is kept at the HHS office and contains *administrative information*, for instance address, contact information, a *list of services the patient is granted*, *notes on special events* and a *care plan*.

• **Delegations** – information regarding all delegations for the HHS are kept at the office.

• **Staff Calendar** - based on individual patient plans, tasks to be performed by staff are added to the calendar and later divided among working staff.

• **Signature list for medication** – a paper located in each patient’s home is signed by HHS each time they distribute medication. This paper contains no information regarding *which* medications were given.

• **Messages/Notepad** - an unstructured notepad is used to communicate within the HHS group. The notepad often contains references to the patients’ binders, indicating that new information has been added there.

As elderly patients often require more advanced healthcare than that provided by the municipality HHS, a DN makes house-calls when necessary. DN often delegates tasks to the HHS and it is therefore important for the DN to keep track of the patients’ progress through the HHS. The DN uses both paper-based and electronic documentation;

• **Nursing Record** – each encounter with a patient is documented in a nursing record, structured according to keywords from the Swedish VIPS-model (Ehrenberg, Ehnfors et al. 1996). The record also contains *risk factors*.

• **Nursing Care plan** – guides the care for each patient, and contains one or more nursing diagnoses. For each diagnosis nursing goals are set up and interventions are planned to meet these goals.

• **Signature list for medication** - is collected monthly by the DN. The list confirms when and by whom the medicine has been dispensed.

• **Calendar** – the DN uses a calendar to keep track of his/her scheduled appointments.

• **Delegations/Instructions** – DNs deliver formal delegations to HHS, through fax, letters or personal handover.

The GP is not as active in the daily care of the patient as the DN and the HHS. However, the GP is often contacted by the DN about issues of medical concern. An appointment at the GP’s office is arranged for formal medical diagnoses. The GP rarely visits the patients in their homes. The GP’s documentation is stored in a medical record, and contains information from patient encounters, medical diagnoses, laboratory results, risk factors and a prescription list containing all medications prescribed by the GP.
With conventional communication and information access in shared home-care (figure 8), healthcare professionals have limited means of reaching information in their mobile work and patients and relatives only have access to paper-based information left in the patient’s home. When necessary the DN brings paper records on a house-call. DNs also use print-outs of required information from the GP’s medical record, for example the prescription list. Both HHS and DNs write short notes on pieces of paper as memory support when working in a patient’s home. On their return to the office they update the information in their respective HIS and inform those who need to know of changes that have occurred.

4.2.2 Intersection points in homecare of elderly

An important result of the case study was the identification of intersection points between different participants in shared homecare. Intersection points in homecare of elderly can be divided into different categories.

- *Initiation of patient-specific changes in homecare provision.* When the initial need for homecare was encountered, patients and their relatives found it difficult to know where to turn. As patients’ health deteriorates, changes in the level of care were required. HHS or relatives are often the first to acknowledge changes in the need for care, and need to inform health and/or social care administrators of the new situation. When re-assessing a patient’s needs, it is important to have a good overview of the patient’s current status as well as recent changes.
• **Consultations.** The patient or relatives often need to contact different care providers. At times, this proved difficult for patients/relatives as the responsibilities of different care providers were unclear and direct contact information for the respective organizations was sometimes lacking. Even after locating the information, reaching the right person was hard and asynchronous ways of communicating were requested. Consultations between different care professionals are also common, yet suffering from similar difficulties.

• **Delegation of duties.** Delegations are an important part of the homecare process, yet information regarding delegated interventions, for example the dispensing of medications, is limited, as well as access to follow-up information that the delegated tasks have actually been performed.

• **Referrals.** Patients are often referred between different care professions and care provider organizations, as responsibilities for different aspects of the care are distributed.

• **Information to other actors.** When important events occur, it may be necessary to inform other actors involved in the care of a patient of these events. Standard information is usually included in the regular HHS briefings which occur at shift handover. However, developing functional systems for informing of unexpected events, such as hospitalization, prove more challenging. In our research, this issue was exuberated by the need to also inform the patient’s relatives. Neither patients nor relatives felt they had genuine understanding of the patient’s planned health and social care activities. For instance, children who lived far away often worried about their parents receiving sufficient care. These relatives often asked for easier ways to be kept informed. Many felt it was difficult to remember information given to them by healthcare professionals. They requested a means to review healthcare information. This included, for example, information provided at a primary care centre appointment or at a care planning meeting.

• **Coordination of planned activities.** Different professionals, as well as patients and relatives, lack overview of the care process. It is difficult to know what interventions are planned, or have already been performed, and when these interventions were to take place.

### 4.2.3 Information requirements as shared information objects

Both general administrative information and patient-specific information are needed by different actors involved in homecare of elderly. General administrative information includes descriptions of homecare organization and governing rules and regulations. Patient-specific information includes practical information, such as contact information and scheduled appointments, and health related information, such as care plans and prescription lists. I will here focus on describing the needs of patient-specific information.
I suggest the design of shared information objects, simultaneously available to both healthcare professionals and patients/relatives. In a mobile environment, the information must be accessible and updatable, depending on the user’s authorization (figure 9). In order to reduce double documentation of work, the solutions should be integrated with current HISs.

Information that needs to be shared includes: the contact information of different care providers; care plans; current medications; risk factors; notes in different records; summaries of for example a patient’s current status and health history; social service contracts; assessments of homecare needs; and calendar information. I have chosen two of our suggested shared information objects to describe in more detail. These shared information objects are used as examples throughout the papers included in this thesis. The shared care plan is modelled in Paper IV, and a shared prescription list is given as an example in Paper I.

**Shared Care Plan**

To ensure quality and continuity of care, the nursing care plan is a key nursing tool used for planning interventions relating to an individual patient’s specific problems (Reed and Stanley 2003; Voutilainen, Isola et al. 2004; Munkvold and Ellingsen 2007). The HHS care plan is sometimes referred to as a Work plan or a Social service plan (Petrakou 2007). In meetings with patients and their relatives HHS set up both social and health related goals, based on an assessment of the patient’s needs with regard to social services. Interventions are planned to reach these goals. Both plans contain informa-
tion which is useful for the other actors. For example, the nursing care plan may contain planned interventions that are delegated to ANs in the HHS.

With DNs, HHS, patients, and relatives all involved in the patient’s care, cooperation, coordination and genuine understanding of the entire care process becomes vitally important. In shared homecare, it would be possible to improve the level of care by better sharing of planned interventions across the range of health and social care professionals involved in the care process. This is particularly important when planned interventions may affect another care professional, or when an intervention demands action by an alternate care professional (Hägglund, Scandurra et al. 2005). Self care interventions may also be included in a shared care plan, enabling families and patients to document performed activities.

The shared care plan needs to include functionality for documentation of performed interventions and their results to enable follow-up and improved quality of care.

**Shared Prescription List**

Many elderly patients have multiple health problems and an extensive list of medications. As they receive care from several care providers, they often have medications prescribed by different professionals making it difficult to keep track of all prescribed drugs. A complete integrated list of medications with instructions should be available to patients and relatives.

In addition to this, HHS, DNs and GPs are all active in the handling of medications and therefore also require a current list of prescriptions. However, this list needs to be adapted to different care professions. For example, the HHS’ view of the medication list should incorporate instructions from the DN. Furthermore, to enable follow-up of delegated tasks and quality control, the signature list is also required by both HHS and DN.

### 4.2.4 Conclusions

My first research objective was to study information and communication needs in shared homecare to determine what information different participants need access to. The case study of information sharing and communication in shared homecare of elderly described in Paper II provides a detailed description of these issues.

A further analysis of the case study materials allowed the identification of information that needs to be shared at intersection points between different actors (patients, relatives, GPs, DNs and HHS). As a step towards the design and development of patient-centred information systems to support cooperation between participants, which constitutes my second research objective, shared information objects were suggested.
4.3 Integration through a Virtual Health Record (Paper III)

My second research objective was to design and implement an integrated application to support patient-centred homecare, exploring how information that is needed by different participants can be made available. Paper III describes the integration architecture of a Virtual Health Record (VHR), designed to meet the needs described in Papers I and II. The suggested architecture enables care professionals and patients/relatives to view or access shared information. The design of the architecture was based on requirements revealed using the MdTS method. This model also integrated numerous legacy systems implementing non-standardised information models. I will now describe how the OLD@HOME VHR meets the needs described in Papers I and II through an integration architecture that enables the creation of shared information objects. I will also discuss the implementation of end-user applications that give access to these objects.

4.3.1 Integration architecture

The purpose of the VHR is to give different user groups access to shared information objects as the ones described in Papers I and II. Different user groups include health and social care professionals, as well as patients and their relatives. Different applications, or views, for different user groups were developed to give access to necessary information regardless of which feeder system it was originally stored in. The applications are not intended to replace current HIS, such as the GP’s and DN’s EHRs, but rather to create what may be described as virtually shared information objects. The shared information objects are virtual in the sense that they are views of data that might be configured differently at different locations but which are mapped into a common format and presented in a single user view (Forslund, Phillips et al. 1996).
The OLD@HOME VHR implements a hybrid architectural approach, making use of a central integration service (the information broker and mediator database) in a distributed environment of applications and feeder systems. The VHR gathers information from three separate feeder systems used by three different care professions (figure 10). Each feeder system is accessed through a web service. Publishing of information from the feeder systems is triggered by an information broker requesting information about patients currently listed in the VHR. The web services deliver information in an XML-file in a pre-defined format. Due to the lack of information standards in today’s legacy systems, a variation in XML-file structures makes it necessary to map each XML-file towards an ideal XML-schema suitable for pa-
tient-centred homecare. The information broker maps the XML-files from the feeder systems against the ideal schema developed in OLD@HOME and sends it as input to a web service which inserts it in a mediator database.

Once information is in the mediator database, users can access their virtually shared information objects through different VHR-applications. Each user role has a specific view, giving access only to information they need and are authorized to read. Two types of applications are available: (1) online web applications used by GPs, DNs and patients/relatives; and (2) an offline application for handheld devices, or personal digital assistants (PDAs) used by HHS staff. Each handheld device has a local SQL CE 2.0 database. Using server based filters, data from the mediator database is then synchronised with the local SQL CE 2.0 databases. This ensures access rights configured according to individual users’ roles. The online web applications interact directly with the mediator database through a roaming session based virtual private network. DN and GP use the same VHR web application, although the content and functionality differs depending on the role and authorization of the user.

The information broker’s primary task is to coordinate information transfer between the VHR and the feeder systems, including the information mapping between the feeder systems and the OLD@HOME ideal XML-schema. The process of information transfer in the information broker can be triggered by different events. The OLD@HOME implementation used time-scheduled triggering, where the mapping process was activated on regular intervals. Other events, such as a request from an end-user application are also possible.

If fully interoperable feeder systems existed, the role of the information broker would simply be to organize the information transfer between the VHR and the feeder systems. This is however not the case in healthcare today, and therefore we chose to implement a solution that included mapping of clinical information towards an “ideal schema”. It would be desirable for such an ideal schema to be compatible with a standard for information sharing, such as ISO/EN 13606 or HL7. In the OLD@HOME case, the choice was made not to focus on any one standard, but to find a solution that met the requirements of the mobile VHR. In Paper IV, I further explore how current standards can be used to represent shared information objects to support patient-centred shared homecare of elderly. Before presenting these results, I would like to describe how the shared information objects are made available to the end-users in the VHR applications.
4.3.2 Shared information in the Virtual Health Record applications

To provide an overview of available information and ease of use of both PDA and web applications, special consideration was given to the design of user interfaces. Important aspects include: identifying the information’s origin, that is, the original feeder system where the information is gathered; supporting staff work processes; and reduction of the number of steps to complete a task (Scandurra, Hägglund et al. 2005). For instance, identification of the information’s origin is done by colour coding. All information from the GP’s system is displayed in blue colour, and all information from the DN’s system is displayed in yellow colour, and all information from the HHS personnel’s system is displayed in green colour. This colour coding allows for the information’s origin to be instantly visible, and this in turn assists with the interpretation of information. I will not go further into details on visualisation and interaction design as these results have been described in other publications (Scandurra, Hägglund et al. 2005; Scandurra, Hägglund et al. 2006a). Instead, I will now describe how the shared information objects presented in Paper II are supported by the VHR.

Both the web applications (figures 11 and 13) and the PDA application (figure 12) use tab based navigation to organize the shared information.

![Figure 11: The VHR web application showing a DN view of the prescription list.](image-url)
Contact information, such as the patient’s address, maps/travel information and contact details of relatives, is available in all applications. Contact information for the patient’s care professionals, such as the HHS contact persons, is also available.

The shared care plan contains information from both the HHS’s care plan and the DN’s care plan. This builds understanding about the work performed by the other care providers, and how this work affects the patient’s health. It is also possible to document performance and outcomes of planned interventions. The overview of the PDA version of the shared care plan is shown in figure 12. The shared care plan is also available in the patients’ and relatives’ web application.

A shared prescription list is also available in all applications (figures 11, 12 and 13). As the current implementation only includes information from three feeder systems, the prescription list contains only the prescriptions documented in the GP’s HIS. In an ideal situation, this list would include all the patient’s prescribed medications. Functionality, as well as the amount of information displayed, differs slightly depending on the current VHR user’s role. In short, each professions view is adapted to their specific needs. A DN for example, is able to provide further information and instructions for HHS and patients or relatives. In contrast, the HHS view provides only a simple
A list of the latest notes (or entries) made by GPs, DNs and HHS in their respective HIS is available in the care professionals’ views. DNs and GPs view all notes, whereas HHS staff has access only to their own and the DN notes. DN and HHS staff can also write new notes in the VHR, which are then sent back to the appropriate feeder system.

Figure 10 shows the shared risk factor field. This field contains information regarding the patient’s risk factors gathered from the respective HIS of the GP, DN and HHS. The information is available in all care professional views. The care professionals’ views also include predefined searches of the GP’s and DN’s record entries, showing the latest entries made including information on the patient’s status and health history.

In addition, the HHS’ PDA application and the patients’ web application contain information from the social services. This includes the list of services a patient is granted according to the social service contract, and the assessment of homecare needs which determines the patient’s need for these services.

The VHR view for patients and relatives also provides a calendar, showing the notes which the HHS have made when they document the services they provide. The patients and relatives can also add personal events in the calendar. Currently, the calendar as implemented in the patients’ and relatives’ view of the VHR does not meet the requirements of the shared calen-
dar suggested in Paper II. Rather, the OLD@HOME calendar acts a tool for patients and relatives to keep track of the care that has been provided.

The VHR also provides mobile documentation functionality. DNs and HHS can document provided care while at the patient’s home, instead of having to wait until they return to their offices. Point of care documentation not only reduces the cognitive work load of care professionals having to remember large amounts of information, but also enables information to be rapidly spread throughout the care providing team.

4.3.3 Results of the VHR evaluations

Different types of evaluations were made of the VHR. The results of a heuristic evaluation (Scandurra, Hägglund et al. 2006b) and a usability laboratory test (Scandurra, Hägglund et al. 2008c) have been published as parts of Scandurra’s thesis (Scandurra 2008). I will therefore not go into details of these studies. In the context of this thesis the reactions of the end-users and their experiences of using the VHR in real life are considered interesting.

The VHR was introduced at the test site and used by care professionals, patients and relatives for a period of 5 months. The deployment process has also been further described elsewhere (Hägglund, Scandurra et al. 2006). Evaluation consisted of qualitative interviews with users, both individual and in groups, primarily focused on understanding and evaluating the users’ experiences from using the VHR. Fears and expectations expressed at the beginning of the deployment were revisited during and after the test period. Any original fears and expectations were also compared against actual problems that occurred in the deployment process and the new benefits that the VHR brought.

Expectations

The analysis of the professionals’ expectations prior to the introduction of the VHR revealed a number of fears. Lack of support for the new ICT from management and from technical support teams and technical problems which would result in disturbance of daily work were fears regarding the new ICT. The time consuming nature of performing everyday tasks in a new work environment, which could impact on the level of care received by the patient was another fear. Lacking usability and/or lack of belief in one’s own capabilities included a fear that the new ICT would be too difficult to learn or too difficult to handle. Fears regarding the functionality of the ICT, and fears that the ITC would be not useful or not appropriately adapted to the relevant work situations were also expressed. There were also concerns about the personal responsibilities of using such a system. This included a fear of making mistakes and a fear of losing or damaging the hardware. Also common were fears related to team work, and many participants were concerned about double workloads, misunderstandings and conflicts within the team.
However, there were also many positive expectations. Two important positive expectations were: *improved work situation*; specifically less paperwork, safer documentation, more meaningful work, and easier and increased access to information; and *personal development*; specifically a strong interest in acquiring new skills, new experiences, and improved competence.

**Results**

Most fears were not realized during deployment of the system. Nevertheless, technical problems and a perceived lack of support remained issues throughout the test period. The technical problems were mainly related to the mobile technology. Despite efforts to make the processes of synchronization and connection to the Internet as smooth and easy to use as possible, there were reoccurring problems where the care professionals were unable to perform these tasks.

Despite the experienced problems, the care professionals felt that the positive outcomes outweighed the problems and adopted the VHR into their daily work. At the conclusion of the project, participating professionals expressed that the VHR had assisted in their personal development and that it had improved their work situations. Increased understanding of the entire work process and improved cooperation within the team were also noted as positive outcomes.

The view for patients and their relatives was tested by a group consisting of two patients and six relatives. By the end of the project, all were convinced that the tool is very important and that it greatly increases safety and trust. Elderly patients are often forgetful and their relatives, especially if living at a distance, have to regularly contact the HHS to keep informed. In this context, the participating relatives found the VHR very useful and usable (Koch, Hägglund et al. 2005).

**4.3.4 Conclusions**

An important objective of my research was to design and implement integrated ICT to support cooperation and information sharing in homecare. Paper III describes the results of this part of my research, in form of a VHR. The VHR applications provide mobile access to shared information objects, such as the ones suggested in Paper II. Different applications, or views, have been developed to meet the needs of different participants. The integration architecture enables mobile access and interaction with information from different feeder systems. This enables a seamless flow of information between all actors involved in shared homecare, and ultimately leads to improved patient-centred shared homecare.
4.4 From clinical requirements to standardized models (Paper IV)

My third research objective concerned standardized information models, and the study presented in Paper IV aimed to explore whether current standards meet the requirements elicited from shared homecare. This research objective was addressed by exploring how standardized concept models and information models can be used to represent shared information objects as those suggested in Paper II. An information model representing a shared care plan was mapped against standardized models, namely the ContSYS concept model, and the openEHR RM. Further, the shared care plan model was transferred into openEHR archetypes, to explore the potential for sharing of clinical information in distributed care environments.

4.4.1 Mapping of the shared care plan to ContSYS

The requirements of the OLD@HOME shared care plan broadly correspond to the ContSYS care plan concept, with the exception that it needs to encompass healthcare activities to be provided to a subject of care by several healthcare professionals. These healthcare professionals may belong to different professions, and to different care provider organizations involved in the provision of shared care. Figure 14 presents a concept model of a shared care plan based on OLD@HOME and ContSYS care plan concepts.

![Concept model of a shared care plan based ContSYS care plan concepts, indicating additions made based on OLD@HOME results](image)
I will here give a short description of the discrepancies between the requirements of a shared care plan (as presented in Papers II and III) and the ContSYS concept model;

- In ContSYS only health care provider activities are included in the care plan concept, whereas in the OLD@HOME care plans it is important to include also health self care activities and health care contributing activities. Such activities are therefore included in our care plan model, as indicated in figure 14.

- Since the shared care plan is a tool for coordinating distributed work, it must be possible to assign a “responsible agent” for each planned activity. The responsible agent may be a family member or the patients themselves. The responsible agent is not necessarily connected to a specific individual, but may be assigned to a group of professionals (such as the HHS). In ContSYS, this relationship is recorded as “is performed by”. This terminology notes only who has planned to perform a scheduled activity, which becomes the person who has performed the activity when it changes status to performed. It is not possible for an actor to plan an activity and declare another actor as the responsible agent.

- In the OLD@HOME model, a shared care plan level is added, which acts as an aggregation of profession-centred care plans. This is done to distinguish between social issues and nursing diagnosis, as well as between nursing goals and social care goals, providing an overview of goals and planned healthcare activities, while preserving the care plans as set up by different professions.

Feedback or outcomes of performed activities also needs to be documented, especially in shared care of chronic patients. Also important are the social services included in the long-term aspects of the care plan. Issues and goals need to be evaluated and updated over time based on the outcome of performed activities. To improve follow-up of the care plan, a connection needs to be made between the care plan and the documented activities. This facilitates important follow-up of the original care plan.

4.4.2 Mapping of the shared care plan to openEHR

An important step towards achieving semantic interoperability is to share a common information model. The OLD@HOME shared care plan was therefore further mapped against the openEHR standard. As openEHR (and ISO/EN 13606) employs a two-level modeling approach, the adaptation of the shared care plan model was performed in two steps. First it was mapped against the openEHR RM, and after that archetypes were designed to represent the concepts of the shared care plan.
The first step of mapping the shared care plan model to the openEHR RM was deciding which types of ENTRY to use for representing the different shared care plan concepts. The openEHR RM separates CARE_ENTRY into four sub-categories: OBSERVATION, EVALUATION, INSTRUCTION and ACTION. A care plan itself was modeled as an EVALUATION, as was health issue and health care goal, as they were all deemed to be assessments or the result of evaluations of observations made regarding a patient’s health.

An instruction is a specification of something that is to be performed in the future (openEHR 2007, p. 59). Instructions were therefore chosen for representing planned activities. In openEHR, the ENTRY subtype ACTION is used to model the information recorded due to the execution of an ACTIVITY by some agent (openEHR 2007, p. 59). We therefore chose to represent the documentation of performed activities as an ACTION.

In addition, the outcome of a performed activity was modeled as an EVALUATION. Both the documentation of performed activities and their outcome may be recorded as entries in an EHR, rather than as parts of the care plan. Within both these types of documentation, it is the connection to the care plan that is most important.

There is no high level grouping class dedicated to care plans in the openEHR RM. It would be possible to group parts of the care plan under a COMPOSITION or SECTION and to create a single archetype for the whole care plan. But it is expected that some care plan content could already exist when a care plan is created. Therefore it is important to have the possibility to group parts of the care plan logically when the plan is authored. LINKs are a good way of logically grouping parts of the care plan. However, a persistent COMPOSITION is proposed as a representation of a shared care plan to include the care plan EVALUATION instances and related health issue and goal EVALUATION instances for care providers to quickly access.
the content of a shared care plan, including material from several care plans used in a shared care context.

**Shared care plan archetypes**

When exploring the openEHR knowledge repository, generic archetypes were found that were possible to use as representations for healthcare issues (openEHR-EHR-EVALUATION.problem.v1) and healthcare goals (openEHR-EHR-EVALUATION.goal.v1). No high level generic INSTRUCTION was available, but it may be possible to reuse instructions for generic procedures, medications, and investigations. These archetypes will however need to be investigated further to determine whether or not they meet the OLD@HOME requirements. A similar situation occurs for ACTIONs, and some common data structure archetypes reused inside INSTRUCTION and ACTION archetypes. A number of archetypes available in the openEHR and NHS repositories are likely reusable directly in the care plan or can be further specialized to meet the requirements of the care plan. Nevertheless, ACTIONs as well as the outcomes of these ACTIONs in the form of OBSERVATIONs or EVALUATIONs are not likely to be included in the care plan itself, but rather as entries in a health record that are linked back to the planned activities in the care plan.

The openEHR repository contained no reusable archetype for the care plan concept. In the NHS repository a plan COMPOSITION was found. However, the archetype was only defined as a generic plan of care, and contained only information regarding healthcare provider and contact details. Therefore a new care plan archetype was modeled using an EVALUATION archetype. Attributes from ContSYS were included in the care plan archetype, and LINKs were chosen to group different archetypes with the care plan EVALUATION.

Finally, a persistent COMPOSITION was used to group the shared care plan concepts. The shared care plan archetype includes one or more care plans, linked to problems, goals, and different types of instructions.

**4.4.3 Conclusions**

My third research objective was to determine whether current standards for information sharing meet the requirements of patient-centred shared home-care. In order to meet this goal, I mapped the OLD@HOME requirements regarding one of the shared information objects to the ContSYS concept

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model and the openEHR standard. The shared information object used was the shared care plan.

The OLD@HOME model and ContSYS model match on a general level. However, certain attributes required by a shared care plan, as specified in Papers I-III, are lacking in the ContSYS concepts. For example the agent responsible for the performance of a planned intervention is lacking in the ContSYS concepts, as is the structure for monitoring the outcome of performed activities. These requirements should be studied further to determine their impact on current standards.

Transferring the conceptual shared care plan model to the openEHR RM proved feasible. An approach using linked ENTRYs enables a care plan structure and allows connection with other parts of an EHR, such as documentation of outcome or information that is already available in the EHR at the time of creating the care plan. In addition, using a persistent COMPOSITION for structuring the shared care plan enables the creation of a long-term care plan that continuously provides an overview of a patient’s health issues and planned care. Reuse of available archetypes from the openEHR archetype repository was also demonstrated.
5 Discussion

The research presented in this thesis had a broad aim to improve information sharing in homecare of elderly. This aim was broken down into three research objectives: the study of information needs in shared homecare; the development of information systems to meet the identified needs; and finally a study of standardized models to explore their usefulness in supporting information sharing in shared homecare.

In accordance with action research and a user-centred design approach, the research was performed in a real setting, involving real care professionals, patients and relatives. By reflection and modification of problems associated with the process of elderly care, the research actively tried to improve the situations of all these participants. In this chapter, I will discuss the strengths and weaknesses of the research methods used, as well as my research results in relation to my research objectives.

5.1 Discussion of research methods

Oates proposes that each research question typically has one research strategy (Oates 2006). She suggests that if more than one strategy is used, it is important to consider what research question each strategy addresses. As this thesis is relatively broad in scope, I have combined three key research strategies. A weakness of this approach is a potential lack of depth in the results. However, as the development of ICT to support patient-centred homecare of elderly has received rather limited attention, I consider it important to explore it from a number of different perspectives. After a broad exploration of the subject has been performed, it is possible to study specific issues and problems in more detail.

Using different research strategies and methods for data acquisition can also be a strength, as it is a form of triangulation. Studying the same phenomena using only interviews will give other results than using only observations. Therefore, combining different methods will provide richer and more valid results. In my research, I believe that the combination of a design and creation strategy with action research and a case study strategy enabled me to reach results that could otherwise never have been achieved. Through these qualitative research strategies, involving study subjects as active participants in the research and actually deploying and evaluating developed
solutions in a real setting, I was able to obtain richer results and more feedback on these results than could have been achieved through a quantitative research strategy.

5.1.1 Generalizations of results
A common problem for both action research and case studies is that it is difficult to make generalizations from the results (Kjeldskov and Graham 2003). The results presented in this thesis are based on a study involving a low number of patients, relatives and participants from different care professions. Despite the variety of ways in which homecare may be organized (Hedman, Johansson et al. 2007), a single homecare area also served as the setting for the different studies, which may also affect the results. Despite these challenges, Oates argues that although some factors in a case study may be unique, it is still possible to generate broader conclusions that are relevant beyond the case-in-study. This is due to the number of similar factors which are typically transferable between cases (Oates 2006).

When comparing the OLD@HOME case to similar settings in Sweden, there is certainly ground for some generalization of our results (Scandurra, Hägglund et al. 2008a). Differences in organization of homecare, as well as cultural differences from an international perspective, will need to be considered for further development of ICT. Despite this, I do believe that underlying issues of support for collaboration to reach patient-centred shared homecare of elderly remain equally important in an international perspective, and that the results presented in this thesis can provide important input in international as well as national arenas.

5.1.2 Impact on participants and results
When using an action research strategy, one of the purposes is to involve participants. It encourages participants both to reflect on their situation and to actively improve it. As a researcher doing action research, I have also spent time in the field, working closely with the participants to improve their situations. Such close personal involvement in the research may also have influenced my results. Working closely with care professionals in the OLD@HOME project, making them reflect upon and analyse their collaborative environment, had an effect in its own right on their cooperation (Koch, Hägglund et al. 2005; Scandurra, Hägglund et al. 2008b). This makes it difficult to state with certainty that the deployed VHR had a positive impact on the care process, notwithstanding the impact the research and development methods had on the participants.

When actively involving participants in development of new solutions, the participants may also become predisposed towards the solution which could bias the results of evaluations. Therefore it would be of great interest
to deploy the solutions in another setting, comparing the results between the two cases. However, such a transition cannot be performed without considering and addressing contextual differences.

5.2 Discussion of results

The research outcomes of my work can be related to my research questions and the papers included in this thesis as is shown in figure 16. The outputs of my research are; (1) a method for analysing and describing collaborative processes and the need for information sharing, (2) an identification of intersection points and information needs in the OLD@HOME case, (3) design of Shared Information Objects to meet the needs for information sharing, (4) design and implementation of a VHR adapted to the requirements of the OLD@HOME case, (5) identification of discrepancies between the requirements of a shared care plan as designed in the OLD@HOME case with the ContSYS standard, and (6) a mapping of the shared care plan model to openEHR.

Figure 16: The relationship between my research questions, papers and the outcomes of this research

I will now continue to discuss these research outcomes, focusing on their respective strengths and weaknesses.
5.2.1 The Scenario method

The development of a new method for analyzing shared care processes was not an initial goal of my research. As work progressed on analyzing these areas, it was however deemed necessary to find a tool to specify them in more detail. Even when extensive effort is put into analyzing the work context using techniques such as interviews, observations and focus groups, it is still difficult to capture cooperative aspects of work and specific requirements of different professions detailed enough to form the basis for development of ICT.

In OLD@HOME, the pre-seminar work, mainly consisting of interviews and observations (Scandurra, Hägglund et al. 2008b) performed before going into the details using scenarios, provided a rich but somewhat fragmented picture of the work processes. If the analysis had not progressed into detailed scenarios and use-cases, the requirements specification would not have captured all aspects of the cooperative tasks. Furthermore, if the scenarios had not been applied as described in Paper I, focusing on future work situations and future work processes, the developed system would only have supported current singular work situations, without improving the cooperative work. Equally, the healthcare professionals would not have achieved such insights into each other’s work, and their collaborative work practices.

Lack of understanding is one of the major issues when developing ICT for shared care. There is general lack of understanding between clinicians and the development team, as well as between healthcare professions. I believe that in interdisciplinary work situations, using scenarios becomes an even more powerful tool to improve communication and understanding between different professional groups. Also, the gap between work analysis and system design was bridged by iteratively transforming scenarios into technical use cases, making the design fully understandable to the developers.

A weakness of this study is the difficulty to determine reliability and validity of the results. As the participants play key roles when using the method, the results may differ depending on the experience and knowledge of the participating healthcare professionals and the participating developers. For its success, it is important to select the right competences. Thus it cannot be assumed that the same results would be found if the study was repeated by different investigators, different clinical participants or indeed by using a competing method. Although in this case it appears that using scenarios to capture shared care processes has been very successful, applying the scenario method in new settings, with new participants will provide more information on potential strengths and weaknesses of this approach. Further application of the method would therefore provide important results for determining the reliability and validity of the method.
5.2.2 Needs for information sharing

My second research objective was addressed through a case study of information sharing and communication in shared homecare. The results were analysed to identify intersection points between different participants, and shared information objects were suggested as a means to support cooperation in shared homecare.

I consider information sharing an important part of collaboration and cooperation. Cooperation is however a complex issue that requires more than just improvement of information access and communication (Bannon and Schmidt 1989; Heath and Luff 1991; Schmidt 1994). I therefore would like to stress the importance of grounding the design of information sharing in a deep understanding of organization and work processes. By designing shared information objects as common information spaces (CIS), it is possible to support cooperation in shared homecare. However to do this, the CIS must become not only a repository of common information, but also incorporate the work practices surrounding that information. This includes considerations such as how the information is used, how the information is managed, and how the information is integrated into the work of those who share it.

Ethical and Legal considerations

When discussing inter-organizational information sharing, it is impossible to ignore ethical and legal aspects.

To protect patient privacy, legal restrictions for information sharing between care providing organizations are usually strict. In Sweden, new legislation for addressing the handling of patient-data was introduced in May 2008. The legislation intends to provide legal possibilities for inter-organizational information sharing, while preserving the patients’ rights to privacy and integrity. The legislation does however not address issues of information sharing between healthcare and social services, which is of importance when working in homecare of elderly.

An important issue when discussing empowerment of patients and family carers is to acknowledge their roles, responsibilities and status in the care providing process, and recognize their responsibilities and status (Nankervies, Waxman et al. 2002). Providing patient-specific information and improved communication facilities is an important step towards recognizing family carers as part of the care providing team. Family carers, often spouses, play a significant role in patient care. These carers may also wish to engage other family members in understanding and sharing care responsibilities (Nankervies, Waxman et al. 2002). A tool that allows several family members to view patient-specific information may improve such involvement. The OLD@HOME case mainly focused on making existent HIS information available to patients and their relatives, but a two-way communication where the voices of patients and family carers may speak directly to the care profes-
tionals is desirable. An important step would be to increase the patients’ involvement in the care planning process, an organizational change in which a shared electronic care plan service may act as a useful tool.

Not all elderly patients will however feel comfortable sharing personal health information with all family members. Naturally, a service making patient-specific information available must be based on patient’s consent. It should also be possible to set different levels of access for different individuals. For example, full information access may be given to one family carer while other family members may view only a limited part. Such access control is of course not only important within families. Patients must also be able to restrict access to their information for different care providers or professions. It is in this area that many ethical issues remain unresolved. Practical solutions to gain and implement patient consent are yet to be examined. Likewise, the consequences of patients denying access to certain information are still unexplored.

In addition to these legal and ethical issues, there will also be important economical considerations that need to be addressed. The financial burdens of implementing and sustaining integrated HIS and eHealth services to the citizens need to be distributed among the care provider organizations. Issues like these need to be studied further.

5.2.3 The implemented VHR

Evaluations of the VHR showed that enhanced information access and knowledge transfer results in greater organizational development and improved inter- and intra-organizational efficiency for the healthcare providing organizations. Time consuming manual information searching was significantly reduced as the relevant information became available at the point of need. Furthermore, involved healthcare personnel gained insight into their own and each others’ work processes leading to an enhanced mutual understanding of the entire care process and heightened awareness of each professional’s respective roles and needs. (Koch, Hägglund et al. 2005)

The implementation of shared information objects in a VHR was however not the only thing affecting these results. The care professionals ongoing cooperation, reflection and analysis of their collaborative healthcare environments also affected their cooperation (Koch, Hägglund et al. 2005; Scandurra, Hägglund et al. 2008b). Therefore, when transferring the VHR to another setting, it is important to make use of an implementation and introduction process that allows the new users to reflect on their work in a similar way, and also to study the outcomes of the intervention in a setting not affected by action research.
**Architectural considerations**

Sommerville identifies five vital non-functional system requirements which have to be considered when selecting a system architecture; *performance, security, safety, availability* and *maintainability/scalability* (Sommerville 2007). Some of these issues are crucial when designing a scalable architecture for inter-organizational information sharing but have not yet been addressed in this thesis. I will therefore discuss them shortly here.

Requirements of performance and availability on handheld devices influenced the decision to use a mediator database. The expressed need of offline access to a VHR in mobile work situations created new problems, with an example being the need for updated information. A proposed solution to this was the two-level synchronization described in Paper III. In this solution synchronization occurs between local SQL CE databases and the mediator database and also between the mediator database and feeder systems. The development of mobile devices and mobile broadband is moving fast, and today the possibilities for development of mobile applications are improved, compared to five years ago. In 2007, the industrial partner XLENT technology upgraded the platform and the HHS at the original test site are currently using their mobile application on smart phones.

Security and privacy issues are of great importance when designing HIS for inter-organizational use (van der Haak, Wolff et al. 2003; Blobel 2006; van der Linden, Kalra et al. 2008). A number of different areas are linked to these issues, such as; authorization, patient consent, role-based access control, digital signatures and patient identification. These aspects are important in all HIS however, they are augmented and complicated when discussing inter-organizational systems. These areas are also closely connected to broader legal and ethical issues. When sharing information among a large number of healthcare professionals and making information available to patients and potentially also family carers or other informal care providers, patient privacy and integrity becomes paramount. Of course, this must be balanced with safe care provision.

Security issues have not been the focus of this thesis, but it is still worthwhile commenting on the relevant security solutions implemented in the OLD@HOME case. The implementation was performed by the involved industrial partners in a professional way allowing for a robust and secure system. Role based access rights were implemented enabling each user group to only access information on patients under their care. Access to the information required was based on the analysis of information needs presented in paper II. Within this system, patients were able to control access rights and to deny certain user groups access to certain information. Although this was possible, no OLD@HOME patients chose to limit access to information. Data transmission was made in an encrypted secure channel. All stored data was encrypted and all security could be managed centrally.
This provided a secure environment for our research project. This level of security was sufficient in our study-sample, but the environment would need to be up-scaled to provide long-term inter-organizational information sharing. The environment would need to include an array of shared resources, such as catalogues of professionals and patients complete with access rights from all the involved care provider organizations. This of course creates a number of new issues that will need to be studied on financial, organizational and legal levels in the future.

5.2.4 Mapping to standardized models

The knowledge and experiences produced by the OLD@HOME case were used as a starting point for modeling shared information objects according to standardized models. The European standards ContSYS and ISO/EN 13606 were chosen for this modeling exercise. Although not covered in the scope of this thesis, it would be of interest to model the same information according to other standards, such as HL7.

The model of the shared care plan needs to be further evaluated in clinical settings. The experiences from work in the OLD@HOME project is an important first step in validating the results however, adaptations made when transforming the care plan model into a standardized format have not been clinically evaluated. The VHR developed and deployed in the OLD@HOME project proved a feasible solution for shared homecare. Despite this, the applicability of the standardized models for information sharing needs further research.

In addition, only one of the suggested shared information objects implemented in the VHR was mapped to standardized models. This mapping identified discrepancies between the requirements obtained from the OLD@HOME case and the ContSYS model. Further mapping of other shared information objects may confirm or change the focus of these results.

Two-level modeling and archetypes

The two-level modeling approach consisting of (1) a reference information model ensuring data interoperability, and (2) archetypes enabling semantic interoperability, has been suggested as a powerful means to separate record keeping concerns from clinical data collection (Beale 2002). Garde et al. identify the need for domain knowledge governance, arguing that archetype development and maintenance needs to be supported and governed by national and international processes to avoid ‘rank growth’ of archetypes, which would jeopardize semantic interoperability (Garde, Knaup et al. 2007). This remains one of the major problems of standardization. To this day it has proven difficult to reach agreement on standardized models, especially when discussing modeling of clinical knowledge.

It has also been suggested that the openEHR archetype approach empowers healthcare professionals to define and alter the accurate knowledge and
information they need in the granularity they need. In the study described in paper IV, domain experts were not actively involved in the actual archetype modeling. Instead, the creation of archetypes was based on available models from the OLD@HOME case. In order to further evaluate and validate the OLD@HOME archetypes, these archetypes should be reviewed by clinical domain experts in cooperation with health informaticians. I further argue that it is crucial to also implement such ICT clinical concepts into real clinical settings so that genuine ‘on the ground’ evaluation may be completed.

In order to achieve full semantic interoperability it is important to combine the use of reference information models with standardized terminologies. It has been suggested that using archetypes for modeling healthcare concepts may facilitate the use of standardized terminologies. Archetypes themselves are terminology-neutral, but can bind to external terminologies like SNOMED CT (Garde, Hovenga et al. 2007). To accomplish bindings with appropriate external terminologies in the shared care plan requires further work. A shared care plan may require different terminologies depending on the different professions involved. In the OLD@HOME case, terminological requirements include standardized nursing diagnosis and interventions, as well as standardized terms for social services.

To summarize, a major part of current research in relation to homecare is still in the explorative phase, describing the problem area rather than providing concrete answers or solutions. In contrast, my work can be seen as leading to improved empirical research, by actually providing some concrete ICT solutions to the shared homecare domain.
6 Conclusions

In the perspective of today’s societal changes, it is crucial to strive for patient-centred shared homecare of elderly patients. My research has focused on: identifying information needs to improve cooperation in shared homecare; enabling a move towards more patient-centred care; and meeting the identified needs through the development of a VHR that integrates information from different feeder systems.

What was known before my PhD?

- Societal changes including decentralization of healthcare and strengthened patient roles require new patient-centred models for care provision. This demands support for both collaboration between healthcare providers in shared care, and participation of patients and informal carers, and ICT has the potential to provide such support.

- Architectures for integration have been suggested, but few studies focus on the homecare environment. There is still limited knowledge about the specific needs regarding information sharing in this area and few HIS have been developed to support patient-centred shared homecare.

- An important area of research concerns standardized information models and standardized terminologies to reach interoperability. However, implications for new requirements, resulting from patient-centred care, on current standardized information models still need to be evaluated.

An action research approach was used to address these issues. Action research can relate to both

- action - practical achievements in the problem situation, and
- research - learning about the processes of problem solving and acting in a situation (Oates 2006).

I will here describe the major contributions made by my PhD research from both of these perspectives, since I consider the action outcomes of my research to be an important benefit and complement to my research outcomes.
6.1 Research contributions

From a research perspective, this thesis provides an important case in which the context and requirements of shared homecare have been explored. This exploration was combined with a practical implementation of a shared HIS – the OLD@HOME VHR – that enables integration of information from legacy systems. The exploration also included the identification of information that needs to be shared at intersection points between different actors in homecare today. It also suggested that shared information objects implemented through ICT can be used to make information available. In addition, important comparisons have been made between the revealed context-dependent requirements of shared care and standardized models.

Through user-centred design methods, such as structured scenarios, a basis for a validated design was created. The process was significant as the design could be understood by both developers and users. Therefore, the gap between work analysis and system design was bridged by iteratively transforming scenarios into detailed use cases. This simultaneously created transparency and traceability in the development process. The developed VHR applications provide mobile access to shared information objects, enabling a seamless flow of information between care providers involved in shared homecare, patients and their relatives.

What has my PhD contributed?

- The thesis gives important insights into specific needs and requirements for information sharing in patient-centred homecare of elderly by identifying and analyzing intersection points between involved actors.
- Shared information objects are suggested as a means to support both collaboration between health and social care and participation of patients and their relatives.
- The results presented in this thesis also include implementation of a virtual health record (VHR) making such shared information objects available through integration of organization-centred legacy systems.
- The underlying information model for a shared care plan was mapped against current standards. Some important discrepancies were identified, stressing the importance of evaluating standardized models against requirements of evolving healthcare contexts.

Finally, the shared care models developed in OLD@HOME were mapped against standardized models. The OLD@HOME model and ContSYS match
on a general level, however some discrepancies exist. To determine how the ContSYS standard will be affected, these discrepancies need further study.

In conclusion, this thesis gives important insights into the needs and requirements of shared homecare, enabling a shift towards patient-centered shared homecare through mobile access to aggregated information from current feeder systems and documentation at the point of need.

6.2 Action contributions

In addition to creating research results, an important purpose of action research is to affect the studied setting in a positive way. In the OLD@HOME project, this revolved around making health and social care professionals reflect on, and take an active role in, the improvement of their work situations.

Different health and social care professions were involved in the project. HHS staff were the largest participating group. Interestingly they were also the group which was most affected by the project. At the beginning of the project, about 40 percent of HHS personnel had little or no experience in computers and information technology (Koch, Hägglund et al. 2005). However, almost all of these HHS personnel expressed a strong desire and strong motivation to learn more about how ICT can assist them in their work.

Moreover, the needs and demands of HHS personnel are often neglected in general healthcare research. The OLD@HOME project was therefore significant as it allowed HHS personnel to cooperatively analyze their work practices, including identifying the advantages and disadvantages of different solutions. As a result of their participation in the action research project the HHS personnel underwent major personal development, becoming more secure in their role and more able to specify their needs with regard to ICT.

Other positive action outcomes of this research relate to the information needs of patients and relatives. The municipality in which the action research was performed quickly responded to the critique related to the difficulties of finding general administrative information, as presented by elderly and their relatives, and updated their web site to facilitate access to important information.

Another important effect on the participating care professionals was their increased knowledge and understanding of their own work processes. Participation by homecare professionals in the research, particularly in the interdisciplinary working groups, also increased mutual understanding of the entire care process, and a greater understanding of how the roles of each care professional linked with those of the others.

The cooperation between researchers and healthcare professionals during the design and development phases resulted in a holistic picture of all care professionals’ work. This holistic knowledge was transferred via the HI-U researchers to the industrial partners, who gained insight into the practical
homecare work which was considered beneficial for the development. The developers showed an increased interest in user behaviour and computer-supported work situations. The cooperation was fruitful also for the research team, who received a robust technical platform, reliable web-based and mobile applications created by the industrial partners using their know-how and powerful development tools. Furthermore, the implementation at the municipality and county council sites was professionally performed, and good relationships were created between the industrial partners and the care providing organizations.

Moreover, the industrial partner XLENT technology developed an ongoing cooperation with the municipality as provider of the HHS part of the VHR. Involved parties in this action research now strive for practical implementation of the research results in a larger scale.
7 Future Work

As a researcher, I find coming up with the right questions to be almost as important as finding their answers. Working with this research a number of different questions crossed my mind. Not all of these could be answered within this thesis. In my future research, I will focus on three important areas of research that the OLD@HOME study demonstrated need further exploration.

7.1 Explore transferability of the VHR

It is known that action research produces knowledge and insights that are grounded in the specific context being studied, and that initial solutions are limited to one test site and not generalizable (Kjeldskov and Graham 2003). However, the outcomes of specific action research may be transferred to similar context through careful interpretation and translation (Miles and Hubermann 1994). Building on this, Boivie argues that the transferability of action research depends on how similar the new contexts are to the original context (Boivie 2005).

The current implementation of the OLD@HOME mobile VHR is rather limited in scope. In order to validate the solution further, it would be interesting to deploy the VHR at other test sites, with other feeder systems and perhaps even in different organizations of homecare. Even more interesting would be to adapt the VHR to a broader domain, particularly one like advanced homecare where different types of medical devices could also be connected to the integration platform. In a situation like this, the VHR could include other types of feeder systems, such as administrative and planning systems. Also interesting would be to continue the evaluation with larger user groups.

The creation of shared information objects will also impact on important security issues, such as inter-organizational authorization, and role-based access to information. In order to create feasible solutions for integrated care, these issues will need further study.

7.2 Further mapping to standardized models

A number of shared information objects were suggested to meet the needs of patient-centered shared homecare. However, so far only one of these objects -
the shared care plan - has been mapped against standardized models. It would be of great interest to continue the mapping of other shared information objects as well. This may reveal other aspects of the requirements of shared homecare which were not revealed by the mapping of the shared care plan.

In addition, there are other standards for information sharing, such as HL7. These standards also need to be explored, determining how they meet the needs of patient-centred shared homecare. A comparison between different standardized information models with respect to their support for the needs of patient-centred shared homecare would also be of interest.

7.3 Explore feasibility of standardized EHR models

In order to fully assess the feasibility of standardized models for supporting patient-centred shared homecare, it is important to implement standardized models of shared information objects in real integration cases. Despite the progress made in this area, more cases exploring the requirements and the challenges to actual implementation are still needed. While initiatives such as IHE are covering important ground, an increase in similar work focusing on the two-level modeling suggested by openEHR and the ISO/EN 13606 standards is also required. As suggested standards are not more broadly implemented in real clinical settings it is impossible to properly evaluate their strengths and weaknesses. The practical use and dissemination of standardized models in healthcare also needs to be increased.

In addition, while it is important to research requirements and ideal structure of an inter-organizational health record, it is also of essence to explore efficient ways to integrate current legacy systems over organizational boundaries. This thesis presents a case in which information is gathered and presented from different feeder systems, yet more work is needed in this area.

In parallel with the research presented in this thesis, there have been substantial efforts put into the area of standardized models to enable interoperability of HIS. As a result, several European and International standards have recently been accepted (EN13940-1 2007; EN 12967-1 2007; ISO/EN 13606-1 2008). Based on requests from the European Committee a Swedish strategy for eHealth was published in 2006 (National strategy for eHealth 2006). This strategy identified six priority areas: (1) bringing laws and regulations into line with extended use of ICT; (2) creating a common information structure; (3) creating a common technical information structure, (4) facilitating interoperable, supportive ICT systems; (5) facilitating access to information across organizational boundaries; and (6) making information and services easily accessible to citizens. Extensive work remains to be completed before the goals of the national strategy for eHealth can be fulfilled. I hope my future research can contribute to these efforts.
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Gränsöverskridande informationsdelning som ett steg mot patientcentrerad hemsjukvård

Denna avhandling i medicinsk informatik består av ett antal artiklar som beskriver behovet av organisationsöverskridande informationsdelning och kommunikation i hemsjukvården, samt utvecklandet av en Virtuell Patientjournal (VPJ) som möter dessa behov. Forskningen har utförts inom ramen för aktionsforskningsprojektet OLD@HOME. Dessutom diskuteras hur internationella standarder för informationsdelning möter de behov som identifierats av dessa studier.


Målen med denna forskning har därför varit att
1) studera behoven av informationsdelning och kommunikationsstöd i patientcentrerad samverkande hemsjukvård,
2) utforska hur integrerade informationssystem kan stödja informationsdelning, samt
3) analysera hur dagens internationella standarder för en obruten vårdkedja och interoperabilitet mellan hälso- och sjukvårdssystem möter dessa behov.
Metod

Forskningen har utförts inom ramen för aktionsforskningsprojektet OLD@HOME (Koch, Hägglund et al. 2005). Aktionsforsknings är en iterativ forskningsprocess som karaktäriseras av att skapa förändring och förbättring av en problemsituation i nära samarbete med deltagarna i en verksamhet. I den aktionsforsknings som presenteras i denna avhandling var deltagarna från olika vårdprofessioner, framförallt hemtjänstpersonal, distriktssköterskor och läkare, samt vård- och omsorgstagare och deras närstående. Studierna som denna avhandling baseras på utfördes i ett område i Hudiksvalls kommun tillsammans med kommunal hemtjänst, primärvårdens hemsjukvårdspersonal och vård- och omsorgstagare och deras närstående. En användarcentrerad systemutvecklingsprocess med fokus på interdisiplinärt arbete i vården (Scandurra, Hägglund et al. 2008b) användes för att utveckla de informationssystem som är en del av mitt forskningsresultat.

Resultat

Resultaten av min forskning presenteras i den här avhandlingen i fyra artiklar. Den första beskriver hur en användarcentrerad metod baserad på strukturerade scenarier kan användas för att beskriva de samverkande processer som präglar hemsjukvården. Inom människa-dator interaktionsforskningen tillämpas scenarier på olika detaljnivå och i olika steg i systemutvecklingen. I det här arbetet användes scenarier för att konkretisera och illustrera situationer där ett IT-verktyg kan användas, för att stötta kommunikationen mellan olika yrkesgrupper och för att underlätta överföring av verksamhetsanalysen till en systemspecifikation där behov och krav från användarna behålls i fokus.

Den andra artikeln beskriver en fallstudie av hemsjukvården i Hudiksvalls kommun. Där sammanställs de situationer då samverkan över huvudmannagränser och mellan olika yrkeskategorier krävs och en specifikation ges av vilken information som behöver delas i dessa situationer. I artikeln ges också ett förslag på en systemdesign för delad information som kan underlätta samverkan mellan olika aktörer i hemsjukvården.

Den tredje artikeln beskriver det system, den Virtuella Patientjournalen (VPJ), som utvecklats för att möta hemsjukvårdens behov av informationsdelning. VPJ ger åtkomst till den information som identifierats som viktig för olika aktörer att ha mobil tillgång till, både generell administrativ information och patientspecifik hälsodata. Designen av VPJ baseras på en arkitektur som möjliggör integration med de olika källsystem som används i respektive vårdgivarorganisation. Aktuell information görs tillgänglig för olika vårdgivare i mobila situationer, med hjälp av mobila verktyg som tabletPCs och handdatorer, samt på webben för vård- och omsorgstagare och deras närstående. De applikationer, eller vyer, som VPJ består av ger alltså olika användargrupper tillgång till den information de behöver oavsett vilken vårdgivar-
organisation som ”äger” informationen. Applikationerna utvärderades grundligt och validerades av deltagarna i OLD@HOME-projektet (Koch, Hägglund et al. 2005; Scandurra, Hägglund et al. 2007; Scandurra, Hägglund et al. 2008c; Engström, Scandurra et al. 2009).


Slutsatser
Sammanfattningsvis så ger denna avhandling viktig kunskap om behoven av informationsdelning mellan olika vårdgivare involverade i hemsjukvården av äldre. Avhandlingen visar också hur mobila IT-lösningar som ger tillgång till delad information skapar förutsättningar för en mer patientcentrerad, samverkande hemsjukvård. I avhandlingen beskrivs också några viktiga skillnader mellan de krav på delad information som identifierats och internationella standarder för att skapa en obruten vårdkedja över organisationsgränser. Detta understryker vikten av att utvärdera standardiserade modeller för informationsdelning mot de direkta behov och krav som identifierats i en klinisk kontext. Ett IT-verktyg, som den Virtuella Patientjournalen, som hämtar informationen från de system som används i vård och omsorg idag och ger möjlighet till dokumentation i mobila arbetssituationer möter användarnas krav på ett användbart och fungerande IT-stöd för hemtjänst- och hemsjukvårdsarbete.
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