Summary
This thesis reports on a study into the care and support needs of community-dwelling people with dementia and their informal carers. To inform people about available healthcare and welfare services that are useful to them, a DEMentia-specific Interactive Social Chart was developed, in short DEM-DISC. The development and evaluation of this system are also described in this thesis. This study was carried out in the framework of the Dutch FReeband User eXperience (FRUX) project.

Chapter 1 reports on the causes and aims of the study. Our society is ageing, and as a consequence the number of people with dementia will grow. The majority of the people with dementia live in their own home assisted by informal carers (mainly spouses or relatives) and in many cases also by professional care services. Because the incidence rate of dementia is expected to double every 20 years and the resources of the healthcare sector are not expected to increase at the same rate as the demand, an enormous strain will be put on informal cares and the available professional care. Care should be provided more efficiently and adequately in the future in order to secure sufficient support for people with dementia.

Taking care of a person with dementia has a high impact on informal carers. Many carers are burdened by the care and experience high levels of distress, anxiety and depression. Carer burden and stress, and unmet needs for professional support are known to be associated with nursing home admission and mortality of people with dementia. To enable people with dementia to stay in their own home for as long as possible it is important to meet their unmet care needs.

Dutch healthcare policy also aims to have people with dementia live in their own environment for as long as possible. With our ageing population, this means that care must be arranged more effectively. A better congruity between care and the needs of clients, in other words a change from a supply-driven to a demand-based healthcare system, can contribute to this. The client in the care system is given a (more) central position and care suppliers are encouraged to become more responsive towards the needs and wishes of their clients. In order to provide adequate and efficient demand-based care, it is necessary to gain insight into the needs of the individual care recipient. Although needs of people with dementia are studied comprehensively, researchers rarely consult them directly about their care needs.

In 2002, in accordance with their policy, the Dutch government opened the healthcare market to commercial parties who could operate and offer their services alongside the public services. Nowadays the offer of healthcare and welfare services is
comprehensive, very fragmented and changing continuously. There is a risk that clients, carers and referrers no longer see the wood for the trees, and therefore do not utilize the broad spectrum of available services in dementia care optimally. The need to create a continuum of flexible and transparent care and supportive services for the different stages of dementia is now generally recognized in the Netherlands. Besides regular professional care, Information Communication Technology (ICT) is since the last decade seen as a promising means to support people with dementia and their carers. Various ICT devices to provide support for dementia symptoms were developed and have in the meantime been proven effective. But ICT applications providing information on the disease and available healthcare and welfare services are never tested on their efficacy, and in general are static and generic systems. A system that can provide tailored advice for specific care needs in dementia, and advises on available health and welfare services in a particular region would support people with dementia and their carers in meeting and alleviating their needs.

Chapter 2 describes the results of an exploratory literature review on the subjective needs of people with dementia. Electronic databases were searched for publications on subjective needs between January 1985 and July 2005, and additional papers were found by cross-referencing relevant publications. Extracts of publications on needs were classified according to problem areas of the (Dutch) National Dementia Program (NDP) and the quality of life domains. Subsequently the extracts were also classified as a "need" (an implicitly communicated felt state of deprivation), "want" (expression of a need) or "demand" (suitable solution to fulfil a need). Subjective needs as reported by people with dementia were found in 34 studies. The studies had various research aims, for example awareness and coping, and few studies focused specifically on the assessment of needs of people with dementia. The majority of the studies were based on small samples and were qualitative in nature. The results indicate that the most frequently reported needs of people with dementia were the need to be accepted and respected as they are, the need to find adequate strategies to cope with limitations, and the need to come to terms with their situation. Explicit wants or demands were expressed less frequently than needs. The high number of reported needs and the limited number of wants and demands shows that people with dementia often do not mention explicitly how they want their needs to be met. Most reported needs were not instrumental, but were related to well-being and coping.

Chapter 3 reports on the results of a large field study on the needs of community-dwelling people with dementia as reported by themselves and their informal carers. The study also provides insight into the service use, agreement on needs within patient-carer dyads, relationships between unmet needs and sociodemographic characteristics, and gaps between needs and availability of services. A large sample of 236
community-dwelling people with dementia and 322 informal carers were interviewed separately in their own homes, using the Camberwell Assessment of Need for the Elderly (CANE) to assess care needs. People with dementia and carers reported that support was needed for many domains of daily living. Most unmet needs were experienced in the domains of memory, information, company, psychological distress and daytime activities; no, insufficient or inadequate support was provided for problems in these areas. The needs carers and people with dementia reported on a group level were quite similar, but people with dementia reported relatively fewer (unmet) needs than their carers; the agreement on needs within patient-carer dyads was low. Type and severity of dementia, living situation and informal carer characteristics were related to the number of reported (unmet) needs and to different care needs. Reasons for unmet needs were lack of knowledge about the existing service offer, a threshold to using services and insufficient service offer. These results provide good starting points to improve community care for people with dementia.

Chapter 4 describes the results of the study on the validity and reliability of the Dutch version of the CANE for use among community-dwelling persons with dementia and their informal carers. The data of the field study on needs in dementia were used to establish the construct validity. Criterion validity and test-retest reliability of the Dutch version of the CANE were established by conducting separate telephone interviews with 69 informal carers. The construct validity of the CANE was good among people with dementia and informal carers. Criterion validity could be studied for 76.9% of the CANE items, and conform the expectations all significant correlations were convergent. Test-retest reliability of the CANE varied from poor to very good and was best on domains where needs were explicit and problems well defined, such as physical health and household chores. The study shows acceptable construct and criterion validity and test-retest reliability of the CANE, and therefore supports the use of the Dutch version of the CANE among community-dwelling people with dementia and their carers.

Chapter 5 describes the development of a DEMentia-specific Digital Interactive Social Chart (DEM-DISC). Community-dwelling people with dementia and their informal carers experience a lot of problems and many of them experience unmet needs with regard to information on the disease and on the available care and welfare offer. They therefore tend not to fully utilize the broad spectrum of available care and welfare services. This can have very negative consequences; DEM-DISC aims to counteract these problems. DEM-DISC is a demand-oriented website for people with dementia and their carers, which is easy to use, accessible and provides users with general and customized information on healthcare and welfare services.
DEM-DISC is developed according to the human-centred design principles: people with dementia, informal carers and healthcare professionals were involved throughout the development process. DEM-DISC was developed from four perspectives. Within the domain-specific content perspective needs and available dementia care and welfare offer were identified. The formulations of the needs were based on the NDP and specific features of services were also inventoried to enable the system to provide customized advice. Within the ICT perspective DEM-DISC was built as a web-based system and the service ontology was developed and tested. Within the user perspective requirements of DEM-DISC were formulated and demonstrators of DEM-DISC were tested for the system’s user-friendliness and usefulness. Within the organizational perspective research was done on a viable business model. The community and the governmental model were found to be the most viable to exploit DEM-DISC.

Finally, a first prototype of DEM-DISC was built with a simple interface, which included the service offer in the region of Amsterdam for five NDP problem areas. Users were supported to clarify their needs in three steps: from a need to a want to a demand. Each demand received an advice on available healthcare and welfare services, and additional information was given, tailored to the preferences of the user if required. Furthermore, the first DEM-DISC prototype contained links to national and regional dementia-related websites and daily news updates on dementia. The conclusion was that the human-centred design was a valuable method for the development of the DEM-DISC.

Chapter 6 reports on the results of the evaluation of the first prototype of DEM-DISC. This study was conducted among informal carers in Amsterdam. During a two-month intervention period the user-friendliness, usefulness and impact of the utilization of a first prototype of DEM-DISC on the daily life of people with dementia and their carers were evaluated within a pretest-posttest control group design. Fourteen informal carers were provided with access to DEM-DISC in their own home, fourteen controls did not have access to DEM-DISC but could only consult their usual sources of information, like printed guides, regional newspapers, the internet, etc. Data were collected through separate interviews with people with dementia and carers at pretest and posttest, by digital logging of DEM-DISC use, short telephone interviews, and with a bottleneck checklist during the intervention period.

Although carers were not explicitly satisfied with this first prototype of DEM-DISC, they found it easy to learn to use DEM-DISC and thought the system was relatively user friendly. After only two months of DEM-DISC use they already reported a higher sense of competence than controls. People with dementia and informal carers in the DEM-DISC group also reported more met and fewer unmet needs.
These positive effects may be caused by the systematic and tailored individual way of information provisioning DEM-DISC offers. We recommend developing DEM-DISC further and conducting a randomized controlled trial into the impact of DEM-DISC use on patients and carers. The impact on nursing home admission and healthcare expenditure are also worth investigating.

**Chapter 7** summarizes the main results from earlier chapters, reports on the main limitations of the studies, discusses scientific, psychogeriatric and societal relevance and considers recommendations for future research and psychogeriatric care that are derived from the results described in this thesis.

Despite the fact that a sample of community-dwelling people with dementia and informal carers was questioned comprehensively about their care needs, the results should be treated with some caution. A relatively large proportion of the non-response was caused by overburden of informal carers, and many people with dementia who lived alone could not be reached. These groups may experience different or more (unmet) care needs that could therefore be underrepresented in our study.

As the circumstances made it impossible to perform an RCT, and we therefore had to perform a pretest-posttest control group trial, the results of the evaluation of DEM-DISC cannot be directly generalized. The first reason is that only a small sample could be recruited due to the specific inclusion criteria, for example computer experience, and with the limited available time to recruit participants. This caused a selection bias: as compared to the control group, there were fewer spouses and more children of people with dementia (with computer skills) in the experimental group. In the analyses we controlled for these differences. Secondly, the DEM-DISC version under evaluation was a prototype, restricted to the city areas of Amsterdam Zuid and Amsterdam Zuideramstel, and it had the possibility to give advice for available care and welfare services on five of the fourteen problem areas of the NDP. Even though this prototype was evaluated by informal carers as relatively user friendly and useful and it seems to have some positive impact on the lives of people with dementia and their carers, the results can not be generalized to all carers with all types of needs living in different parts of the Netherlands.

The results of our field study on needs in dementia contribute to the knowledge on needs that community-dwelling people with dementia experience. Many studies have been conducted on needs in dementia, but they fail to report on the needs of people with dementia and their carers separately. Additionally we studied the agreement on needs within patient-carer dyads. We also showed that service offer was available for the most common unmet needs.

The development of DEM-DISC is unique and contributes to the growing knowledge on assistive technology of people with dementia and their carers. Information sys-
tems on dementia and care and welfare services are available, but were never evaluated with (potential) users on their user friendliness, usefulness and impact. Professional carers in psychogeriatric care should take into account that the opinions of people with dementia and their carers are complementary. They should also pay attention to characteristics that are related to a higher risk for unmet needs, like having another type of dementia than Alzheimer’s disease, severe dementia, separate households, and informal care provided by non-spouses, younger, female or burdened persons.

DEM-DISC may help to improve the dementia healthcare and welfare offer in a region by giving insight into the gaps in the existing offer for specific care needs. Because DEM-DISC is a demand-oriented system, care and welfare providers need to shift from supply-driven to a demand-oriented service offer that puts their (potential) clients first. The resulting insight into (un)met needs in dementia provides policymakers with the information they need to change the existing care system into a more demand-oriented system.

As DEM-DISC is developed with potential users, DEM-DISC is expected to give users an easy tool to make informed choices on the type of care that meet individual demands and to use available care more effectively. Targeting and alleviating unmet needs in time, may enable people to live in their own home for a longer period of time, thereby possibly postponing nursing home admission and even mortality. Furthermore, the costs of health care could be reduced.

Successful implementation of DEM-DISC requires that it is further developed, using human-centred design principles. Before considering implementation on a large scale, the effects of DEM-DISC use should be studied with the fully developed version by means of an RCT. Only than can statements be made about the generalizability of possible effects. In addition to the effects of its use by informal carers, future studies should also focus on DEM-DISC use among people with dementia and professional carers and on how they experience its’ user friendliness, usefulness and impact.

The results described in this thesis can support care professionals to better tailor their care to the needs and demands of their clients. To assess the needs of people with dementia, we recommend the systematic use of the CANE in dementia care practice.

With the development of DEM-DISC both dementia care providers and care users are being served: DEM-DISC procures dementia care providers with a tool to create and maintain a care chain in dementia practice, because it helps to identify needs and lacunas in the service offer in a region. By solving the unmet needs and filling the lacunas, a balanced continuum of dementia care in a region can be created that focuses on people with dementia in different stages of the disease. On the other hand, DEM-DISC provides user groups with relevant information on supportive services, it dis-
closes the care offer in a region and makes the service offer easily accessible for potential users. It is therefore expected that DEM-DISC will ultimately contribute to a better quality of care, to more effective care use and, as a consequence, to a better quality of life for people with dementia.