Summary

Due to the aging population worldwide, the number of people with dementia is expected to increase dramatically in the next decades. This also means that the number of people that are available to care for these people with dementia, will decrease. As such, innovative and efficient solutions are needed to help people with dementia in their daily lives. In this thesis, we developed and researched several innovative care technology solutions that aim to help people with dementia, their informal caregivers, and professional carers. The first intervention we developed and studied is the ROSETTA system, an integrated system that assesses safety in the home, monitors behavior, and helps participants outside their homes (Chapters 2 and 3). The second intervention, Into D’mentia, aimed at helping informal and professional caregivers gain insight into the behavior of people with dementia, by having them experience a day in the life of someone with dementia (Chapters 4 and 5). In the STAR study, we developed and researched an online eHealth course on dementia care, which helped informal and professional caregivers to understand and deal with dementia (Chapter 6). Finally, we studied an online patient portal that allowed people with dementia and informal caregivers to find information on dementia; to contact other people; and to view their appointments and contact their physician directly (Chapter 7). Below, we summarize the results of these studies.

Chapter 2: ROSETTA: Participatory designing of domotica

The ROSETTA project offered an integrated, personalizable assistive technology solution that could be installed in participants’ homes, and aimed to support people with dementia and caregivers by providing communication tools, a photo book and an on-screen agenda with reminders, a fall detection system, a behavior monitoring system, and GPS tracking for outside. It helped informal carers by offering a sense of security regarding their family member with dementia, and helped them manage the agenda of their family member. The chapter reports on the user-participatory designing of the ROSETTA system through several workshops and meetings in three phases of the development of the system: initial development, development, and fine-tuning. This was done in the Netherlands and Germany; in Belgium only the UAS-AAPS was evaluated in this project. The workshops included design mockups, system pilot tests, and system tests in a demonstration home. Of the possible functionalities that were discussed, people with dementia and informal carers considered the following functionalities most helpful and relevant: help in cases of emergencies, navigation support and the calendar function with reminders. Dementia experts rated various behaviors as being relevant to be monitored for the timely detection of changes in functioning, e.g., eating, drinking, toilet usage, taking medicine adequately and appropriately, performance of daily activities and sleep patterns. The user-participatory design process resulted in valuable input from persons with dementia, informal carers and professional carers/dementia experts, based on which a first prototype of the ROSETTA system was built.

Chapter 3: ROSETTA: Evaluating domotica

This chapter describes an exploratory evaluation study in which the usefulness, user-friendliness and impact of the ROSETTA system developed in the previous chapter was tested among people with dementia, their informal carers and professional caregivers involved in the care. The ROSETTA system was installed in participants’ homes in the Netherlands, Germany and Belgium. In a controlled trial with pre-test and post-test measures, participants took part in semi-structured interviews regarding usefulness and user-friendliness of ROSETTA, and completed impact measurement questionnaires on, among other things, Quality of Life, perceived autonomy, caregiver feeling of competence, and use of
care services. All participants stated that ROSETTA is a (very) useful development. Since the current system was a first prototype version it was not rated highly on user-friendliness, especially the user interface for the caregivers. This was mainly caused by budget- and time constraints during the development. We found no significant effects on any of the impact measurements.

Chapter 4: Into D’mentia: Designing and developing a dementia simulator

This study describes the preliminary study performed for the development of Into D’mentia, a mixed-reality simulation that lets visitors experience a day in the life of someone with dementia. For an accurate representation of their experience, this study aimed to find the most important domains of experience for people with dementia. This was achieved by performing an international literature search for articles containing quotes by people with dementia about their experience. These were categorized according to three domains: problem areas, adaptation-coping, and Quality of Life. The quotes were discussed regarding their recognizability and relevance for people with dementia during two focus groups with people with dementia and two with informal carers and by an online survey with professional carers. In the focus groups, especially quotes in the adaptation-coping domains were recognized by people with dementia and all caregivers. The domains regarding Quality of Life were also recognized by most participants. The problem areas of the National Dementia Programme were recognized to a lesser extent.

Chapter 5: Into D’mentia: Evaluating a dementia simulator

The Into D’mentia simulator offers informal carers and professional caregivers the chance to experience first-hand the effects dementia has on a ‘day in the life’ of someone with dementia, with the aim to improve their understanding of, and empathy for, the person(s) with dementia they care for. During this ‘day’, techniques such as sensors and projections simulate the limitations and social and emotional consequences of having dementia. The simulation made informal and professional caregivers think about how they would cope and deal with the effects this disease has. It confronted them, for example, with forgetfulness, disorientation, and the social stigma one experiences as well as the emotions these provoked. Both informal carers and professional carers indicated they felt Into D’mentia was a highly useful and user-friendly innovation that offered them an immersive means to learn about the effects of dementia. They indicated the simulation helped them to offer better care. Participants mentioned that they often thought back to their experiences in the simulation in their daily practice, to better understand the behavior of people with dementia. No significant effects were found on impact measurement.

Chapter 6: STAR: developing online e-learning for caregivers

The STAR E-learning course helped informal carers, volunteers, and professional carers in their understanding of, and dealing with, dementia. The course consisted of 8 different modules with specific themes and 3 difficulty levels (basic, intermediate and advanced). In a Randomized Controlled Trial with pre-test and posttest conditions across two countries, the user-friendliness and usefulness of STAR were evaluated among laypersons (informal caregivers and volunteers), and professional caregivers. The different users appreciated the STAR course positively: most users indicated the course was helpful, useful, and user-friendly. They scored the contents of the modules with an average score of 8.0. Additionally, significant positive effects were found on several impact measurements: the (in)formal caregivers’ person-centered care approach as well as the total score on positive attitudes towards
dementia improved in both the experimental and the control group increased in score. Significant improvements were found in the STAR training group on empathic distress, empathic concern, and on the ability to take the perspective of the person with dementia. Professional caregivers improved on empathy. In addition, after the course carers also had an increased sense of competence, meaning that they felt better able to take care for the person with dementia.

Chapter 7: DAC: Evaluating a web-based patient portal

The Digital Alzheimer center (DAC), an online patient portal, helped people with dementia and their carers by offering information, communication and peer contact tools through an online portal. The DAC was studied in a descriptive study among patients, carers, and health care professionals. Mixed methods were used, consisting of observations; an online survey and semi-structured interviews. A majority considered the DAC useful; most notably for understanding dementia. Fewer people found the DAC user-friendly: only a minority indicated that they found the site easy to work with. In semi-structured interviews the site was generally rated positively on usability and usefulness and design of the website/interface. As the majority of users evaluated the usability and usefulness of the portal positively, and appreciated the information it provided, it was concluded that an online patient portal could be a useful means to help to support patients and carers in dealing with dementia. However, as only a minority of patients found it easy to work with the portal it was also concluded that good, cooperative design and frequent usability testing is essential to offer a good online portal.

Chapter 8 General discussion

Chapter 8 contains a short summary of the research and studies performed, and describes these in relation to other scientific literature. Additionally, it describes methodological considerations, recommendations for future research and daily care practice, as well as recommendations for developing care technology and supportive technology.

It first describes how most of the systems were designed in a user-participatory design process. In this design process, it is important to involve future users (people with dementia, informal carers, and/or professional carers) of a system as early as possible, to ensure a system that matches their needs and wishes. We concluded, based on the different studies performed, that it is feasible to involve our intended target groups. However, we did find that despite a user-participatory design process, some interventions were still considered to be non-user friendly. This highlights the complexity of designing (assistive) technology solutions. Second, it described how users evaluate the systems that were studied in this thesis; these were analyzed on user-friendliness, usefulness, and effectiveness (in achieving the intended aims).

The experienced user-friendliness of the interventions was variable; it depended greatly on the level of development of the system how this was experienced. Besides, it was important to communicate with users, to manage expectations of the system. On usefulness, all solutions were found to be considered very useful. The studied interventions were considered useful to enhance feelings of safety, to enhance understanding, empathy and sense of competence in family caregivers, and to provide information. Nearly all users agreed that developments such as the interventions studied were ‘indispensable for good care in the future’. With regards to the effectiveness of the systems, it was concluded that it was not possible to find effects with small-scale prototype studies (such as ROSETTA), whereas larger-scale, more developed systems (such as Into D’mentia and the STAR e-learning) found effects
on (reduced) caregiver stress, higher sense of competence, and on empathy and understanding to-
wards people with dementia.

The main methodological issues that we encountered were: the level of development of the interven-
tion; the influence this had on user satisfaction and experience of user-friendliness; the small user
groups in some of the studies, which influenced the statistical power to find significant effects; and the
possible user selection bias, which may have influenced the results by only including those with a pos-
itive attitude towards technology.

Scientifically, this thesis add to the growing body of knowledge on e-health and assistive technology,
offering new insight into research in surveillance systems, dementia experience, online e-learning, and
online patient portals (specifically for people with dementia and their informal carers). With regards
to societal relevance, this thesis describes several possible solutions to support people to deal with the
increasing burden of dementia. Finally, recommendations are made for future research into assistive
care technology for people with dementia, and the application of such technologies in clinical practice.