

## **Preface**

This master thesis has been written for the master's degree Health Sciences of the University of Twente. The subject is the development of a viable business model in health care. It concerns the development of a viable business model for a Dynamic Interactive Social Chart for DEMentia care ('DEM-DISC'). The study was conducted within the Telematica Institute. The assignment was part of the Freeband User eXperience (FrUX) health care project.

I would like to thank my supervisors of the University of Twente; Professor van Rossum and Dr. Hummel for their guidance. Professor Van Rossum contributed to the approach of the conducted study and textual styling. Dr. Hummel's support realized adequate application of the Multi Criteria Analysis, one of her areas of expertise. Without support and confidence of my colleagues of the Telematica Institute this thesis would not have been written. I would like to thank Timber Haaker for all his patience and support in a busy period as well as Henny de Vos, Edward Faber and Jan Gerrit Schuurman. I enjoyed my time in the Telematica Institute, which provided me an opportunity to see how research is conducted in knowledge institutes.

A valuable contribution was the time and interest participants to the interviews dedicated to the interviews. Their opinions were indispensable. I thank all participants. Based on their even larger and respected contribution I would like to name Marcel Garritsen, Marcel Assink and Rene Brandhoff.

Last but not least I would like to thank family and friends for support and understanding in a period in which I dedicated too little time to them.

Saskia Moen

## **Executive summary:**

Within the Freeband User eXperience (FrUX) health care project a Dynamic Interactive Social Chart for DEMentia care ('DEM- DISC') is being developed. The aims are that the social chart enables users to find relevant customized and context sensitive packages of care to match their needs, resolve fragmentation issues and improve accessibility of health care and welfare. Due to the increase of the ageing population the number of persons with dementia will increase. The increase in the number of patients places the health care system in a situation where considerable challenges can be expected. Based on a study conducted by FrUX researchers to assess' needs of patients and informal carers it was concluded that patients need information on the diagnosis, their condition, support opportunities, support with memory problems and personal care appointments. Informal carers need information on diagnosis, prognosis, treatment, day care facilities, other services and both legal and financial issues. ICT seems applicable to provide information. A prototype of 'DEM- DISC' is being developed (Dröes R. M., Meiland F. J. M. , van der Roest H. G., Maroccini R., Slagter R., Baida Z., Haaker T., Kartseva V., Hulstijn J., Schieman R., Akkermans H., Faber E., Tan Y.H., 2005) .

Market adoption of innovations is a difficult and complex process. This formed the reason for a study into viable business models for 'DEM- DISC', which is the subject of this thesis. The main research question is: 'Which organizational arrangement may lead to a viable business model for 'DEM-DISC'?'

No theories exist on how to design business models in health care. An exploratory approach is required. The STOF model from the Freeband Business Blueprint Method (Haaker T., Oerlemans K., Steen M., de Vos H. 2004) will be applied in the study. The STOF model distinguishes four domains within a business model; a service domain, a financial domain, an organization domain and a technology domain. The four fields describe the business model. A business model may be considered viable if it creates value for both users and providers. The STOF model provides the basis to construct organizational arrangements which may eventually result in viable business models. The study includes a stakeholder analysis, an orientation on competitive offerings for 'DEM- DISC' and a market analysis. The identified stakeholders were approached to participate in interviews. In the competitive offerings analysis no competing offerings were found in the Netherlands. Although the concept of 'social charts' is emerging, none are fully completed or provide the combination of clarification of needs and matching resources. It revealed several organizational forms in which the leading role was played by different parties, e.g. commercial parties, governments or interest groups. Previously a symposium was organized by the project group in which possible business models or approaches were discussed (see: Hulstijn, J., Haaker, T., Huisman, E., Meiland, F., Slagter, R. 2005). The combined approaches resulted in 5 organizational arrangements; a 'care providers' model', an 'insurer model, a 'governmental model', a 'community model' and a 'commercial model'. An organizational arrangement is considered an important element of business modeling, based on the Freeband Business Blueprint Methodology (FBBM). An organizational arrangement reveals required roles and who may fulfill those roles. Absence of detailed revenue sharing distinguishes organizational arrangements from business models.

Interviews were conducted with identified stake holders. Within the interviews topics discussed were the value proposition, the potential organizational arrangements of 'DEM- DISC' and relevant financial matters. 'DEM- DISC's' service concept was appreciated by interviewed

stakeholders. Revenue sharing was considered important. Several non material benefits were mentioned as benefit. Participation of a patient/consumer organization was highly valued. Quality of data is very important but hard to accomplish due to annual changes in product range as a consequence of market reforms. For instance purchasing of extra mural care will more and more be done via tender based on price and quality. Entry barriers for new providers have diminished. Each year new providers will provide a range of new products. Adjournment of partitions results in freedom to specialize in a variety of target groups for extra mural care. As a defense to market reforms one witnesses an increase in mergers. A limited number of providers have to compete with each other to expand their market shares resulting in a fear of competition which might influence cooperation. Financing structures do not stimulate efficiency outside one's own organization. Nobody feels responsible for fragmentation issues.

All interviewed parties valued 'DEM-DISC's' aims. All wish their services will be included, especially when a large number of providers participate. Participation of a large number of providers changes fear of competition in fear of not being included in the system. Value is created for patients and informal carers. The interviewed parties expect that more informal carers than patients will use the system. For them the overview of available products is valuable. It supports the assessment of options for new product development and provides information in preparation for tender procedures. The system provides a channel to potential clients. Information on user preferences for services and percentage of clients who use Internet as source for information could be generated by the system and is considered valuable by providers.

Outcomes of the interviews were discussed in three expert interviews to assess if results formed a representative sample. Based on interview outcomes one organizational arrangement was discarded. It was the 'Insurer model' which was not feasible based on the separation in the financing structure between 'care' and 'cure'. Furthermore the interview outcomes were processed in criteria for a hierarchy for the Multi Criteria Analysis. Comments of participants of the interviews were recapitulated in critical success- and design factors of the FBB methodology. A sample of the interviewed stakeholders participated in the Multi Criteria Analysis. The formulated criteria were: 'acceptable profit sharing', 'clear division of roles', 'quality of data' and 'acceptable network strategy'. Participants reached consensus with respect to the criteria. Relative weights were assigned to the criteria by the participants. The alternatives were the four remaining organizational arrangements. Alternatives were compared by pair wise criteria from the hierarchy.

The Analytic Hierarchy Process (AHP) was applied to select the best possible business model for 'DEM- DISC'. The results of the AHP show the 'community model' is the best choice for a viable business model based on the participants' opinion (n=2) with respect to the criteria. The participants valued the 'commercial model' most for its cost benefit perspective based on the criteria 'acceptable profit sharing'. With regard to 'clear division of roles', 'quality of data' and 'acceptable division of roles' the 'community model' was preferred best. The 'community model' seemed to create the best match between 'network value' and the most 'customer value'. Participants believed this model would guarantee a long term interest in maintaining up to date information and a remaining interest in offering the service to users. With regard to the governmental model they felt distrust regarding its interest in maintaining adequate data of information. Since governments have multiple tasks, it was assumed interest would be limited to obtaining the service, instead of maintaining quality of the site. The 'commercial model' and the 'care providers' model' enclose a commercial interest. A commercial interest would not establish credibility among users according to the participants and disappointing results might influence the long term perspective.

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## Chapter 1: Introduction

The study for a viable business model for 'DEM- DISC' is conducted within the Freeband health care project. The health care project is embedded in the Freeband program.

### **Freeband program:**

The FrUX project is part of the Freeband Communication program and stands for Freeband User eXperience. Freeband aims to generate public knowledge in advanced telecommunication (technology and application). It aims especially at establishing, maintaining and reinforcing the Dutch knowledge position at the international forefront of scientific and technological developments, addressing the most urgent needs for research and novel applications in the presence of unfolding new technology. The Freeband program comprises more than 25 organizations, including all important technology providers and many representative end- user organizations. The Dutch Ministry of Economic affairs is co- funding this program as part of the BSIK plan<sup>1</sup>. In Dutch: "Besluit Subsidies Investerings Kennisinfrastructuur."

Freebands vision for 2010 is to consider communication and information from the perspective of the user and not the provider. Communication infrastructures will become transparent and abundant in all their layers. Freeband addresses the knowledge chain in communication in the direction of this new ubiquitous paradigm. Based on this vision key research questions are raised in three main themes:

- Society, users and applications: "What are the new possibilities in different sectors for ubiquitous communication and ambient intelligence, what do they presuppose as knowledge and how can they be realized?"
- Networking, service provision and generic user interaction: "The telecommunication infrastructure viewed from the user's perspective."
- Enabling technologies: "No new services emerge without adequate technology; conversely, it is the technology that drives the new paradigms!"

### **Freeband health care:**

The health care research focuses on supporting chronically diseased patients and both their professional and informal carers. Within this increasingly growing target group the limitation is the elderly that suffer from dementia. This group is an interesting target group because it presents the health care system with considerable challenges. There is a growing need for support of elderly people with dementia living in the community and their carers, because of factors such as scarcity of professionals, limited availability of sheltered housing (homes for elderly and nursing homes) and the preference of elderly people to stay in their own environment as long as possible.

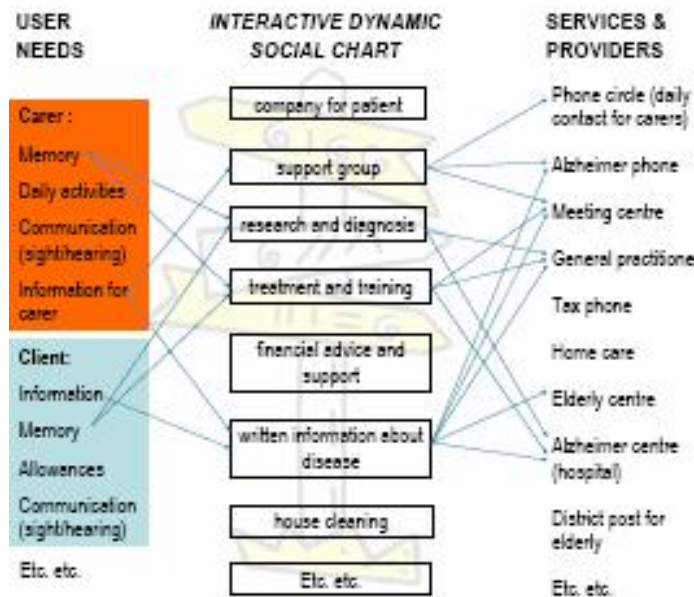
FrUX is directed toward we-centric services and to service bundling. The health care project within the FrUX project aims to develop an interactive, dynamic social chart for dementia care. The aim is to investigate and develop new innovative (mobile) services to support elderly people with chronic diseases who live in the community and their (in-) formal carers. The pilot focuses on people with dementia and their (in-) formal carers (Dröes et al 2004). In the health care project there is cooperation between Ericsson, TNO, Waag Society, VU medical center,

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<http://www.ez.nl/dsc?c=getobject&s=obj&!sessionid=1cL9!DmQ!2AD1FIodrhuUhcT3M4aGBJh@SuGEX@lW9pD8XH1!b8xG1jiflWxRze8&objectid=18962&!dsname=EZInternet&sitenam=EZ-nl&loggetobject=true&isapidir=/gvisapi/>

Webintegration and the Telematica Institute. Users will be enabled to find relevant personalized, context- sensitive bundles of services to match their needs. Needs are systematically clarified by an interactive model and interface which enable users in an specific context to articulate manifest, latent and slumbering needs. An ontology will match needs and services and present a list of results to users. Figure 1 visualizes what an ontology can do.



Examples based on preliminary results from our field study on needs in dementia

Figure 1: Matching needs and resources by means of an ontology.

### ‘DEM-DISC’

‘DEM- DISC’ is an innovative service concept in health care for people suffering from dementia, their informal carers and health care professionals.

DEM- DISC is a service that aims to:

- Improve accessibility of healthcare and welfare offerings by providing a single point of entry: “anywhere, anytime, anyplace”;
- Enable users (patient, informal carers and professionals) to find services for their specific needs;
- Advise users about bundles of care and welfare services depending on their specific needs (customized and context sensitive);
- Create collaborative business experiences between care and welfare organization in a region;

Implementation of DEM-DISC might lead to an improved quality of life of persons with dementia, alleviation of carer tasks, transparency of service offerings, less fragmentation of care, a continuum of care and welfare services and efficient and customized service delivery.

### Problem description:

The problem is that available services to support persons with dementia and informal carers cannot be found because of fragmentation issues. Informal care is relevant in the perspective of dementia. About 60% of care for dementia patients is provided by informal carers (Duijnste 1996). Informal carers sometimes dedicate 24 hours per day to caring for the patient (Mercken 2005). Although many carers experience satisfaction on provision of informal help (Nolan, Grant

and Keady 1997) the intensive task evokes a risk of overburden (Mercken 2005 and Timmermans 2003). Informal care should never be seen as a way to solve problems of under capacity. Patients should be able to rely on the fact that content and scale of professional care facilitates prevention of overburden of the informal care system (Gezondheidsraad 2002 and Mercken 2005). In order to realize the scenario recommended by the Dutch Health Council and the Dutch Institute for Care and Welfare (NIZW, Nederlands Instituut Zorg en Welzijn) it is a necessary condition available services can be found by patients and informal carers. Within the FrUX health care project a Dynamic Interactive Social Chart for DEMentia care is being developed. The aims are that the social chart enables users to find relevant customized and context sensitive bundles of care to match their needs, resolves fragmentation issues and improves accessibility of health care and welfare. Due to the increase of the ageing population the number of persons with dementia will increase. The increase of the number of patients presents the health care system with considerable challenges. Based on a study conducted by FrUX researchers to assess the needs of patients and informal carers it was concluded that patients need information on the diagnosis, their condition, support opportunities, support with memory problems and personal care appointments. Informal carers need information on diagnosis, prognosis, treatment, day care facilities, other services and both legal and financial issues. ICT seems applicable to improve provision of information. A prototype of 'DEM- DISC' will be developed.

Since market adoption of innovations is a difficult and complex process a part of the study is devoted to exploring viable business models for 'DEM- DISC'. The research goal is to design a viable business model for 'DEM-DISC'. Viability is assumed when both the users of the system and the providers of the system perceive sufficient value of their participation (Dröes R. M., Meiland F. J. M., van der Roest H. G., Maroccini R., Slagter R., Baida Z., Haaker T., Kartseva V., Hulstijn J., Schieman R., Akkermans H., Faber E., Tan, Y. H. 2005). No theories exist on how to design a business model in health care. An exploratory approach is required (figure 2).

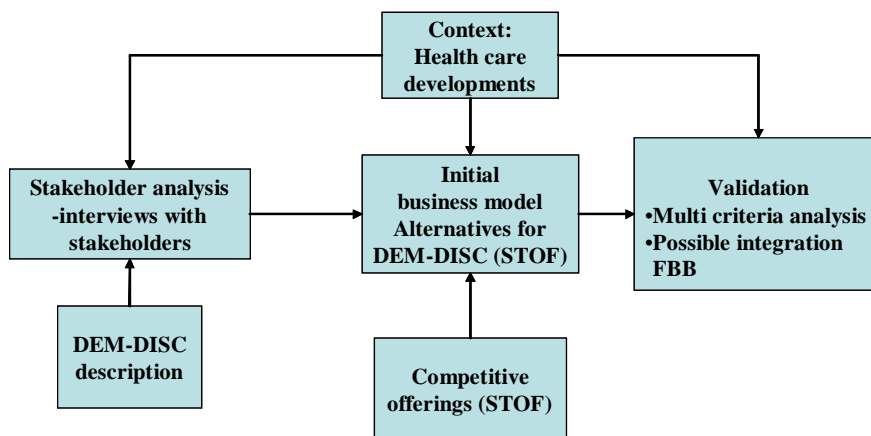


Figure 2: Exploratory approach of the study

The STOF model (Haaker T., Oerlemans K., Steen M., de Vos H. 2004) will be applied to explore possible viable business models. This model is very well applicable because it consists of all basic elements to construct a business model. The STOF model separates four fields within a business model; a service domain, a financial domain, an organization domain and a technology domain. The four fields combined should deliver network value and customer value. Based on the STOF model it is possible to construct organizational arrangements which may eventually result in viable business models. The research question is: "Which organizational arrangements may lead to a viable business model for 'DEM-DISC'?" Based on results of the study for viable



business models the Telematica Institute aims at elaboration of the FBB method for application in the field of health care.

**Reading instructions:**

The second chapter provides information on the collective noun ‘dementia’. The chapter discusses forms, signs and stages of dementia and needs of dementia patients. Furthermore the function, role and relevance of informal carers and their needs are described. The last topic is legislation for both patients and informal carers and its consequences for business modeling opportunities. The general information combined provides insight on which problems ‘DEM-DISC’s’ value proposition should concentrate.

Chapter 3 describes ICT and the role it might play for dementia care. General examples of ICT applications and those specific for dementia fill the first section. It explains that ICT is a logical solution for both patients and carers with respect to information needs. The chapter will be concluded with a description of the aims of the prototype of ‘DEM- DISC’ in development, its aims and effects and relevant elements with regard to online delivery of long term health care revealed by literature.

Methodology and research approach of the study at designing a viable business model for ‘DEM-DISC’ is the subject of chapter 4. The fifth chapter describes the theoretical framework from which the study has been conducted. The applied theory will be described as well as the organizational arrangements which were developed based on this study.

Outcomes of interviews and the Analytic Hierarchy Process are presented in chapter 6. These outcomes reveal viability of the developed organizational arrangements in their function as preliminary business models. Opinions of participants of the interviews reveal their views on added value, sources of revenue and indirect revenues delivered by ‘DEM-DISC’.

Chapter 7 presents the conclusion and contains discussion over the results, as well as limitations of the conducted study.

## Chapter 2: Dementia, Informal care and Policy

Dementia is a collective noun for different types of dementia. The first four paragraphs attempt to contrast differences in this noun 'dementia'. Disorders can be classified in different ways, a classification scheme attempts to group disorders. There are different forms of dementia within this classification. Although all types and forms differ there are general symptoms which can be signs of dementia. As the disease progresses the need for care increases. Care demands of persons with dementia conclude the overview of general dementia information.

The second topic is informal care. Dementia is a disease in which informal care plays a major role. Patients need intensive support. When available, informal carers are a possibility in provision of care. Care for both patients and informal carers is available via the AWBZ.

The government created funds and policies to enable informal carers to care. Due to the deteriorating character of dementia and the related need for intensive care it is clear that policies do not prevent problems, such as overburden of carers.

The last topic is an orientation on business modeling opportunities. Described legislation forms the framework of the area in which business modeling opportunities should arise. Does legislation provide chances to create collaborative business experiences between care and welfare organizations in a region?

### 2.1 Dementia

Dementia is a collective noun. In the vernacular used by laymen several types and forms of dementia are united. The following classification exists for types of dementia<sup>2</sup>.

CLASSIFICATION	
Cortical dementia	Brain damage occurs in the brain's cortex or outer layer and tends to cause problems with memory, language, thinking and social behavior.
Sub cortical dementia	Affects parts of the brain below the cortex and tends to cause changes in emotions and movement, as well as problems with memory
Progressive dementia	This type is progressive and it results in gradual interference with more cognitive abilities.
Primary dementia	Primary dementia is such as Alzheimer's disease and a common feature is that the disease is no consequence of another disorder
Secondary dementia	This type occurs as a consequence of a physical disease or injury.

Table 1: Types of dementia

<sup>2</sup> retrieved from:

[http://www.freetipson.co.uk/healthcare/dementia/different\\_kinds\\_dementia.html](http://www.freetipson.co.uk/healthcare/dementia/different_kinds_dementia.html) on 10-08-2006

Some dementia types fit into one or more classification. For example Alzheimer's is considered both progressive and cortical.

### 2.1.2 Forms of dementia:

Forms of dementia are<sup>3</sup>:

FORM OF DEMENTIA	DESCRIPTION
Alzheimer's disease	Alzheimer's disease is the most common form of dementia which accounts for 50- 70% of all cases of dementia. Alzheimer's is progressive and degenerative. Brain cells shrink or disappear, abnormal material builds up in the cells in the brains and plaques form on the outside of cells. Cells die and information cannot be recalled or assimilated. Alzheimer's affects each area of the brain and functions or abilities are lost over time. Vascular dementia is a broad term for dementia types associated with problems of circulation of blood to the brain. Vascular dementia is the second most common form of dementia. Vascular dementia and Alzheimer's can appear similar; this mixture is a common cause of dementia.
Vascular dementia	Vascular dementia is a broad term for dementia types associated with problems of circulation of blood to the brain. Vascular dementia is the second most common form of dementia. Vascular dementia and Alzheimer's can appear similar; this mixture is a common cause of dementia.
Parkinson's disease	Parkinson's disease is a progressive disorder of the central nervous system. Symptoms are characterized by tremors, stiffness in limbs and joints, speech impediments and difficulty in initiating physical movements. In later stages some people develop dementia.
Dementia with Lewy bodies	Dementia with Lewy bodies is caused by degeneration and death of nerve cells in the brain. The disease is named after the abnormal spherical structures, which are called Lewy bodies. Patients can suffer from visual hallucinations and experience stiffness or shakiness. Patient's conditions fluctuate. Dementia with Lewy bodies can occur similar to Alzheimer's or vascular dementia
Huntington's disease	Huntington's disease is a rare hereditary degenerative disease.
Korsakoff's syndrome (Alcohol related dementia);	Korsakoff's syndrome (alcohol related dementia) is a preventable type of dementia caused by too much alcohol and a diet with a shortage of vitamin B1 leading to irreversible brain damage.
Dementia related to AIDS	Aids related dementia is called the AIDS dementia complex. The dementia is a complication which can results from human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS). Without taking anti-HIV drugs the dementia may be developed in the later stages of the disease.
Fronto temporal Lobar Degeneration (FTLD)	Fronto temporal lobar degeneration is the name of a group of dementias that involve degeneration in one or both of the frontal or temporal lobes of the brain. This group includes fronto temporal dementia, progressive non- fluent aphasia, semantic dementia and Pick's disease. Symptoms vary. The degree of involvement of frontal and temporal lobes and the affected side of the brain result in the variation.
Creutzfeldt-Jakob disease	Creutzfeldt Jakob disease is an extremely rare and fatal disease caused by a protein particle called prion. Usually the disease progresses rapidly. Symptoms

<sup>3</sup> retrieved from:

[http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Dementia\\_different\\_type:s?OpenDocument](http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Dementia_different_type:s?OpenDocument) on 10- 08- 2006 (last reviewed July 2006)

	like failing memory, changes of behavior and lack of coordination are followed by pronounced mental deterioration, involuntary movements, blindness, development of weakness in arms or legs and finally a lapse into coma.
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Table 2: Forms of dementia

### 2.1.3 Signs of dementia

Early signs are subtle and vague. Often it is not obvious what signs mean or how they should be interpreted.

- Progressive and frequent memory loss;
- Confusion;
- Personality change;
- Apathy and withdrawal;
- Loss of ability to perform every day tasks<sup>3</sup>;
- Inability to speak or act purposefully;
- Disturbance in executing functions (planning, acting purposefully);
- Changes in mood (depression, euphoria, irritability);
- Disturbed reality testing;
- Disturbances in the motor system<sup>4</sup>;

### 2.1.4 Stages of dementia

The process of dementia is one of deterioration. There is no effective therapy to cure the disease. The deterioration process consists of different stages. In each stage the demand for care and support increases. The patient is less and less capable of living independently. Dependence of informal care and professional care increases for the patient in order to prevent institutionalization. Where support starts with encouragement to perform daily tasks the last stages of the disease require full time supervision and nursing duties such as taking care of incontinence and alternating positions in bed to prevent bedsores.

The stages in table 3 explain the deterioration of the patient and loss of capabilities and can be understood by people with no medical background.

STAGES	DESCRIPTION
Preliminary stage:	The practicing of work activities results in major problems
Stage 1: 'Stimulating'	Conducting domestic tasks which require planning and insight becomes impossible. Useful day activities succeed only with help. Patients need to be encouraged to perform daily chores and physical care.
Stage 2 'Intervention and supervision':	Most activities are too complex; parts of activities can be conducted with supervision. The care taker should initiate and choose for activities which stimulate remaining functions of the patient. Contact with other people is very difficult due to the incapacity of the patient to express him/herself adequately. Physical care has to be conducted with supervision.
Stage 3 'Partial take-over':	The patients understanding of his or her body is lost. Even the urge to use a toilet is no longer understood by the patient, as well as reasons why a toilet is used. Acts and movements become disorderly and loose purposiveness
Stage 4: 'Stage of full take-over'	Last remaining of verbal capabilities of expression are lost. Gradually all movements and initiative to move are lost; first walking, subsequently standing

<sup>4</sup> retrieved from: [www.bruggerbosch.nl](http://www.bruggerbosch.nl) on 10-08-2006

	and sitting, movement of the head and finally the movement of arms
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Table 3: stages of dementia

There are methods for professionals to examine a patient’s cognitive function. An example is the Mini Mental State Examination (MMSE). Scores divide dementia in mild, moderate or severe (Folstein M, Folstein S, McHugh P. 1975).

### 2.1.5 Needs of persons with dementia

Within the FrUX project a study to reveal needs of dementia patients has been conducted. The study focuses on subjective needs for care and support. Subjective needs are experienced by persons themselves and can be latent or manifest. Objective needs are perceived and expressed by professionals, often based on standardized measurements. A study conducted by the VU medical center among 60 persons with dementia revealed needs and unmet needs of this group. The most frequent reported needs are; accommodation, memory, money, household activities, physical health, food, mobility, day time activities, eye- sight/ hearing and self care. Most frequent reported unmet needs are information regarding health and treatment, memory, psychological distress, company, deliberate self harm, day time activities, benefits, money, intimate relations and psychotic symptoms.

A literature study (n=23) has been conducted to assess if a literature study would reveal the same needs of persons with dementia. The study is conducted by Dröes R.M., Van der Roest, H. and Meiland F. and revealed comparable needs (Dröes et al 2005). Table 4 provides an overview of conclusions. Needs are coded and classified in the problem areas of the National Dementia Program (see appendix B) (Meerveld, J., Schumacher, J., Krijger, E., Bal, R., Nies, H. 2004) and the Quality of Life domains (Dröes, R.M., Boelens, E.J., Bos, J., Meihuizen, L., Ettema, T.P., Gerritsen, D.L., Hoogveen, F., Lange, J. de, Schölzel-Dorenbos, C., 2005).

PROBLEM AREAS NATIONAL DEMENTIA PROGRAM (appendix B)		DOMAINS OF QUALITY OF LIFE	
12x	C-NDP-9: Loss	11x	C-QOL-2: Self-esteem/self-image
6x	C-NDP-2: What is the problem and what can help?	11x	C-QOL-4: Social contact
5x	C-NDP-1: Feeling that something is wrong	9x	C-QOL-7: Physical and mental health
4x	C-NDP-3: Frightened, angry and confused	9x	C-QOL-11: Being useful/giving meaning to life
4x	C-NDP-13: Miscommunication with formal carers	8x	C-QOL-10: Self-determination and freedom
3x	C-NDP-5: Avoiding contacts	7x	C-QOL-5: Enjoyment of activities
2x	C-NDP-4: Having to face everything on your own	5x	C-QOL-1: Affect
2x	C-NDP-14: Resistance to institutionalization	5x	C-QOL-3: Attachment
1x	C-NDP-11: Being patronized by formal carers	4x	C-QOL-9: Security and privacy
1x	C-NDP-6: Physical care	2x	C-QOL-8: Financial situation
1x	C-NDP-8: Medical problems as well	2x	C-QOL-12: Spirituality
0x	C-NDP-7: Danger	1x	C-QOL-6: Sense of aesthetics in living environment

Table 4: Needs of persons with dementia. Retrieved from: Dröes et al 2005

Interpretation of the different problem categories lead tot the conclusion that persons with dementia want information on the diagnosis, their condition, support opportunities, support with memory problems and personal care appointments (Dröes et al 2005).

## 2.2 Informal care

Millions of Dutch people care for relatives or friends and neighbors who are sick, disabled or dying. The Social Cultural Planning office of the Netherlands (SCP) estimated a number of 3.7 million people in 2001. The carers are called ‘informal carers’.

There are several definitions to describe what informal care is. All definitions carefully distinguish informal care from paid help and organized voluntary work. “Offering help to family members or close relatives who need help because of health problems” (Timmermans 2003). “Care that is not provided as a consequence of a profession, but is directly distributed to a person in need by one or more members of his or her direct environment, in which help is a direct consequence of a social relation” (Kwekkeboom 1990).

Informal care exists over a wide range of tasks; domestic help, personal care (help with washing, clothing, getting in and out of bed) called All Daily Living events (ADL’s), psycho social assistance (physical presence, listening, comforting) and sometimes nursing help. For dementia patients 60% of required care is provided by family (Duijnste 1996). On average informal carers dedicate 17 hours of each day to caring for a dementia patient. Tasks and load are dependent on presence and availability of professional care (Mercken 2005). Without informal care patients might have to turn to more professional care, or even institutionalization.

Informal carers themselves often experience satisfaction on the provision. Their motives are love, affection and casualness. Nolan, Grant and Keady (1997) found that the aspects that result in satisfaction for informal carers are:

- Providing meaning and organization of someone’s life;
- Pride in discovering possibilities;
- Meeting the wishes of the cared for;
- Remaining dignity of cared for;

For some people the provision of informal care can imply an enlarged risk of- overburdening, resulting from difficulties in space or time, combination of employment and informal care and financial consequences (Mercken 2005 and Timmermans 2003). Signals of overburden are physical complaints, psychological complaints and behavioral complaints.

<b>Size of overburden</b>	<b>% of all informal carers</b>
None or almost none	29%
Somewhat	45%
Rather	19%
Heavily burdened or overburden	7%
Total	100%

Table 5: Size of overburden for all informal carers of all patient groups, derived from Factsheet EIZ (2003)

## 2. 2. 1 Needs of informal carers of persons with dementia

Caring for a person with dementia can be an enervating task which implies an emotional, physical, social and in the long run, a financial burden (Morris, R. G., Morris L. W., Britton, P. G. 1988, Huckle, 1994, Dunkin and Anderson- Hanley, 1998, Gwyther 1998).

In order to assess the needs of informal carers of persons with dementia researchers within the FrUX project conducted interviews and a literature study. A study conducted by the VU medical center revealed needs and unmet needs of informal carers (n= 108). Needs were revealed by conducting interviews and coded by the Dutch version (Dröes, R. M., Hout, H. P. J., Van der Ploeg, E. S., 2005c) of the Camberwell Assessment of Needs in of Elderly (CANE) (Reynolds, T., Thornicroft, G., Aba, M., Woods, B., Hoe, J. , et al. 2000).

The most frequently reported needs of informal carers of persons with dementia stemming from the interviews are; memory, money, household activities, food, self care, daytime activities, physical health, mobility, medication and accidental self harm. Unmet needs are; memory, daytime activities carer information, information regarding health and treatment of persons with dementia, eyesight/ hearing, continence, carer distress, psychological distress, psychotic symptoms and mobility. An unmet need is a condition or series of conditions that exist when the burden of providing care either exceeds the resources of an individual or creates some deficit in the life of that person (Branch 2000).

The researches conducted a literature study (n=29) as well. The problem areas of the National Dementia Program and the Quality of life Domains for informal carers were used to categorize outcomes (Chappel and Reid 2002). Chappel and Reid based their model on Michalos's modified Life Satisfaction Scale (Michalos 1985). For parts of the literature study abstracts were used, as a consequence full paper texts could indicate some differences in presented figures, outcomes should be interpreted with some caution.

	PROBLEMS IN NATIONAL DEMENTIA PROGRAM		DOMAINS OF QUALITY OF LIFE
14x	IC NDP 4: Having to face everything on your own	8x	IC QOL 7: Recreation activity
13x	IC NDP 2: What is the problem and what can help?	3x	IC QOL 2: Finances
12x	IC-NDP-1: Feeling something is wrong	3x	IC-QOL-3: Family relations
9x	IC NDP 6: Physical care	3x	IC QOL 6: Relationship partner
7x	IC-NDP-3: Frightened, angry and confused	2x	IC-QOL-4: Friendships
8x	IC NDP 10: Miscommunication with formal carers	2x	IC QOL 5: Housing
5x	IC-NDP-12: For better and for worse	2x	IC-QOL-8: Religion
2x	IC NDP 8: Loss	2x	IC QOL 9: Self esteem
2x	IC-NDP-5: Avoiding contacts	0x	IC-QOL-1: Health
2x	IC NDP 7: Danger	0x	IC QOL 10: Transportation
2x	IC-NDP-10: Cannot cope anymore		
2x	IC-NDP-11: Being patronized by formal carers		
2x	IC NDP 14: Resistance to institutionalization		

Table 6: Needs of informal carers. Retrieved from: Dröes et al 2005

The analyzed data lead tot the conclusion that informal carers want information on diagnosis, prognosis, treatment, day care facilities, other services and both legal and financial issues (Dröes et al 2005).

### **2. 2. 2 Dyad**

A person with dementia and an informal carer form a dyad. The needs of the carer and the cared for person with dementia are intertwined. Sometimes they conflict (Procter and Testad 2005). Carer and cared for people often have the same interest, but they can also diverge. For example, respite is a service that can be highly valued and desired by the carer, but the cared for person can feel 'a burden from whom relief is needed'. Respite is a short term admission to institutionalized care, which provides the carers a break from caring. Tensions around the dual focus involve the question about who is properly considered the subject of welfare interventions (Twigg 1996). It affects the definition of services for carers. The context of dual focus produces two perspectives, specific carer services like support groups and breaks from caring, and carer allocations. Carers also receive help from services aimed at the person they care for. Daycare is such an example, the service is aimed at the cared for person, but also relieves the carer. In social policy there is a general acceptance that what counts as a service for carers needs to be considered widely. Twigg wrote: "...the majority of help that comes to carers does so from services primarily aimed at the person they look after. Because of the close interrelationship between the carer and cared for person this is relevant to the carer also" (Twigg 1992:60).

### **2. 2. 3 Relevance of informal care to dementia**

The deteriorating character of dementia evokes a patients' need for intensive care. A large percentage of care (60%) is distributed by informal carers (Duijnste 1996). Informal carers experience positive feelings as a consequence of caring (Nolan et al 1997).

Due to the proportional increase of the ageing population, an increase in the number of patients is to be expected. Dementia cannot be cured and there are no effective drugs to influence the degenerative character of the disease. As a consequence each patient develops an expanding need for care. Patients seem to prefer to remain independent for as long as possible (Dröes et al 2005). The intramural capacities do not come up to the mark (Gezondheidsraad 2002). A combination of provision of professional care in combination with informal care is considered to be able to postpone permanent institutionalization (Pickard 2004). This has two advantages; capacity of intramural care is spared and patients are enabled to remain independent.

To support this statement some figures regarding dementia. In the Netherlands about 250.000 people suffer from a form of dementia. About 12.000 patients are under 65 years. From all people over 65 years about 7% suffers from dementia. Over 80 years of age this percentage is 20%. Since females live longer than men, about 71% of the patients are female (Alzheimer Nederland, 2003). 65% of dementia patients live at home, assisted by volunteers and professionals. Even patients with average to severe or severe dementia still live at home. Family and social networks play an important role in caring for people suffering from dementia. Caring for someone with dementia who lives independent is time consuming. In three quarters of the cases the elderly need help daily, sometimes even 24 hours a day (Mercken, 2005). For half of these cases this care is completely or partial a responsibility of partners or family. Most of these patients visit a form of daycare. Admission to institutional care can be postponed until the time the informal care no longer manages to provide care. The percentage of patients that stay in either nursing homes or homes for elderly is around 17% and 18%.

The increase of the ageing population will lead to an estimated population of 350,000 people suffering from dementia in 2020. In 2050 the population is estimated to rise up to 580,000 patients. The expected proportional increase of the ageing population is problematic for health care. Demand might exceed supply. In 2000 35% of people suffering from dementia were admitted to residential care. This calculation leads to the conclusion that in 2010 12900 more



places are needed than are available. This means that every year an extension of 1300 intra mural places is required (Gezondheidsraad 2002).

Furthermore calculations suggest that one of every four persons of the working population should be employed in health care, in order to answer to the expected demand (Twentse Courant Tubantia 28-05-2006). In 2000 there were 63 potential employees for each dementia patient. In 2010 this number will be reduced to 55 and in 2050 only 27 (Gezondheidsraad 2002).

The Dutch Health Council and the NIZW recommend that informal care should never be seen as a way to solve problems of under capacity. Patients should be able to rely on the fact that content and scale of professional care facilitates prevent overburden of the informal care system. They state that emotional support of informal carers enlarges capacities, but as well can result in a realization that the provision of informal care is too much to handle (Gezondheidsraad 2002, Mercken 2005).

## **2. 3 AWBZ**

This section describes the Exceptional Medical Expenses Act (AWBZ) because this law forms the framework to which the business model should be compatible.

### **2. 3. 1 The AWBZ process en functions**

Dutch uninsurable care is reimbursed based on the AWBZ. The AWBZ mainly exists for long term care, which is called uninsurable care. Every inhabitant pays a contribution to the AWBZ. The Act is based on an altruistic conviction, one of the fundamentals of a welfare state.

The provision of care for patients under the AWBZ begins with a needs assessment. The needs assessment shows the character of conditional entitlement. In case a patient satisfies a number of conditions the entitlement will be assigned in the needs assessment. The needs assessment results in claims. These claims are divided in functions and classes. There are seven functions and the classes determine the severity of care expressed in hours. With this claim the patients can apply to the health care office or a provider of care. The Netherlands are divided in 32 regions; each region has its own health care office. The regional's largest health care insurer organizes the execution of the health care office. Care can either be distributed in kind (by a provider) or patients can apply for a Personal Budget in order to arrange their care independently by managing their own budget. Figure 3 illustrates the process:

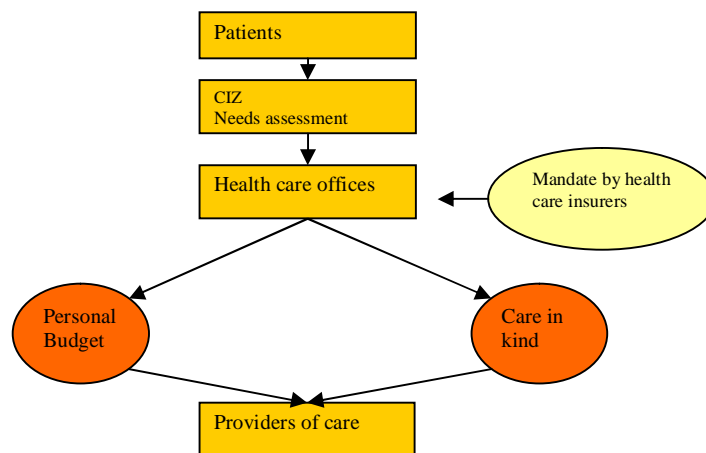


Figure 3: Conditional entitlement for distribution of care under the AWBZ Act

The 7 AWBZ functions are:

1. Domestic care;
2. Personal care;
3. Nursing;
4. Supporting guidance;
5. Activating guidance;
6. Treatment;
7. Residence;

Patients with a Personal Budget (PB) can only use the first five functions, since PB's do not cover residential care. Treatment as well as residential accommodation is provided by intramural providers. The classes are the number of hours per function one is entitled to.

Expenditure on uninsurable health care distributed under the AWBZ is strictly separated from health care expenditure on 'cure'. The AWBZ covers severe medical risks. Dementia is such a risk. Individual insurance is unavailable. Costs of (distributed) care can hardly be afforded by anyone. The AWBZ covers expenditure for inhabitants of the Netherlands. An insured person is insured by his or her own health care insurer. The AWBZ contribution is included in a levy on wages for social insurance (in 2006: 12.55%). The costs of 'cure' are financed via a mandatory health insurance (Ministerie Volksgezondheid, Welzijn en Sport). Expenditure in 2005 under the AWBZ is 12.3% of the Gross National Product (SCP Statline). Care is reimbursed, but users do have to pay a mandatory private payment.

Dementia is a costly disease. In 1999 the disease was the most costly per case of the disease. The table shows 98% of expenditure was made up of distributed care under the AWBZ. Only 2% was reimbursed via the mandatory health insurance.

Diagnose group	Total cost (in million euros)	Share in total expenditure (%)	Share in AWBZ (%)	Share in 2 <sup>nd</sup> compartment	Costs per case of the disease (euros)
Dementia	1760	4.9	98	2	30614
Mental disability	2780	7.7	100	0	27245

Oesophageal cancer	23	0.1	4	96	22411
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Table 7: Costs per disease. Derived from De Jong et al (2005). Appendix A contains the full table in Dutch

This section revealed that care for dementia patients is distributed under the AWBZ. Patients can receive a claim via a needs assessment from the first stage of the disease. For example a patient receives a claim for three hours of home care for help with washing and clothing and 16 hours of daycare, or the equivalent in a PB. With this claim the patient is enabled to remain independent.

### 2.3.2 Informal care policies

The AWBZ consists of different money flows. The subsidy for informal care support is called the 'Coordination Voluntary Homecare and Informal Care' (Coördinatie Vrijwillige Thuiszorg en Mantelzorg, CVTM). The Ministry of Health, Welfare and Sports yearly distributes 11.34 million euros for support of informal care (Schreuder- Goedheijt 2004). Funds made available for support of informal care by the government are distributed via CVTM.

Different initiatives to support informal care are financed with these budgets. Support of informal care is available ranging from a national to a local scale. Health Care Offices are enabled by the government to distribute the CVTM subsidy for 'Steunpunten Mantelzorg' (stations of support for carers), 'Vrijwillige Thuiszorg' and coordination and support of these organizations. Local governments contribute as well to the financing of these organizations (90% AWBZ and 10% local government).

'Steunpunten Mantelzorg' provide support for informal carers. Carers can find information, participate in training, courses or support groups. As well they can ask for volunteers to assist them. 'Vrijwillige Thuiszorg' is an organization, often included in 'Steunpunt Mantelzorg' that has a number of volunteers that can be linked to informal carers and help with domestic jobs or stay with the cared for, when the informal carer is absent.

The national organization 'MEZZO's' task is informing and supporting informal carers. They organize trips (with discount) for informal carers in order to 'relax'. There is also a phone number from where personal information can be requested. Mezzo organizes these tasks together with 250 regional organizations, like 'Steunpunten Mantelzorg'.

In 2001 the national government published a White Paper on informal care. Plans were to reinforce the support of carers, the promotion of voluntary work, the development of respite care, the care in crisis situations, to study effects of informal care, to measure the combination of paid and unpaid work and the role of carers among professional carers. The aims were:

- Better co-operation between informal and formal caregivers (allocation of tasks, communication, attitude);
- More attention for informal care in professional training programs;
- Developing and extending respite care services at home (Schreuder- Goedheijt 2004);

Financial compensation for informal carers is available via:

- Income tax measures;

- Income support;
- A paid career break (Care leave, for instance Calamity leave, Short term care leave, the Act Financing Career Breaks and life course schemes);
- Insurers via compensation for respite care;
- Measures by local authorities;
- Payment by the care recipient who has a Personal Budget (the one cared for can pay the carer a wage) (Schreuder- Goedheijt 2004);

### **2. 3. 3 AWBZ and Societal Support Act**

The Societal Support Act (Wet Maatschappelijke Ondersteuning, WMO) will replace some parts of the AWBZ. The Societal Support Act is a new law that will come into force on 01-01-2007. One part is the support of informal care, and second is the function domestic care. Patients who wish to apply for former AWBZ functions now will have to turn to their local government. The national governments developed a framework of the Act. Local authorities have opportunities to organize the Act on a desired local level. As a consequence the local authorities themselves are responsible for execution and justify their policy to their citizens. The motivation to change legislation can be found in efficiency and improving social structures; stimulating participation of all groups within a society.

## **2. 4 Modernization of the AWBZ**

Since 2003 the AWBZ is being modernized by gradually introducing regulated market forces. A health care office each year purchases care based on expected demand. A part of extramural care is purchased via a percentage of existing contracts and an increasing part is purchased via tender. Welfare services are purchased by local authorities via yearly tender procedures. Selection in tender procedures is based on both price and quality. Intramural care providers receive funding via subsequent calculation, a tariff for each nursing day. All expenses must be covered by this budget. A conversion from previous received annual budgets. Entry barriers have diminished for extra mural care. Access to the market does not guarantee products are purchased by the health care office. Adjournment of partitions realized providers of extra mural care are no longer obligated to specialize in one target group.

As a result of market reforms it can be seen that there is a rise in mergers. Providers consider merging as a defense against the introduction of market forces. As a consequence the choice in providers is limited; mergers result in increases of scale. Each remaining provider tries to expand his own market share. Cooperation is considered a threat. Providers advertise in order to attract new clients; they prefer to conduct advertising by private service departments. It gives them the opportunity when a potential client contacts them to fulfill the clients' needs from their own supply. These service departments are paid for by funds for care. Expansion of production over the contracted production is impossible because of the purchasing function of the health care office. Efficiency incentives are absent; producing as much as possible is the providers aim and his means to generate income and attempt to extend market shares. No one feels responsible for fragmentation issues. From the providers perspective that is a responsibility for the government.

Policies aim to intermediate between availability, accessibility, affordability and increasing expenditure on health care costs. Chapter 3 will assess the role of ICT in dementia care. Based on this it can be decided whether ICT could function as a supplement to policies' aims.

### Chapter 3: The role of ICT in dementia care

People with dementia want information on the diagnosis, their condition, support opportunities, support with memory problems and personal care appointments. Informal carers want information on diagnosis, prognosis, treatment, day care facilities, other services and both legal and financial issues (Dröes et al, 2005).

The most frequent mentioned unmet needs for both informal patients and carers categorized in the problem areas of the National Dementia program (NPD) (Meerveld et al, 2004) and CANE (see appendix B) are:

**Patients:**

- Feeling something is wrong;
- What is the problem and what can help?
- Frightened, angry and confused;
- Social contact (CANE);
- Physical and mental health (CANE)

**Informal carers:**

- Feeling something is wrong;
- What is the problem and what can help?
- Physical care

Available services to fulfill needs cannot be found by patients and carers. A gap analysis proved services do exist and are available (Dröes et al, 2005). Information is hard to find caused by fragmentation. There is no single point of entry where general information and information on care and welfare are available. ICT can fulfill the need for information experienced by patients and informal carers. ICT techniques are suitable for structuring, searching for and delivering of information. The need for information was found in several studies such as the study of the Health Council (2002) and the NDP (Meerveld et al, 2004) which was conducted based on the outcomes of the study by the Health Council and ordered by the Ministry of Health, Welfare and Sports. Section 3.1 will demonstrate why ICT can be considered suitable to fulfill needs of patients and carers.

### 3.1 Examples of ICT in (dementia-) care

In the introduction of chapter 3 the suggestion was made that dementia related needs of patients and carers might be fulfilled by ICT solutions. An overview of available ICT services or services in development for care in general or dementia is presented. Based on presented services the relevance and applicability of ICT for health care is explained.

AIMS	FORM	DESCRIPTION
Information on service offerings specific to dementia	<a href="http://www.Alzheimer-Europe.org">www.Alzheimer-Europe.org</a> <a href="http://www.alzheimers.org.uk/Your_local_branch/index.htm">http://www.alzheimers.org.uk/Your_local_branch/index.htm</a> <a href="http://www.alz.org/carefinder/index.asp">http://www.alz.org/carefinder/index.asp</a> <a href="http://www.alzheimersdisease.com/index.jsp?usertrack.filter_applied=true&amp;Novald=335011946769793039">http://www.alzheimersdisease.com/index.jsp?usertrack.filter_applied=true&amp;Novald=335011946769793039</a>	Information on dementia can be found worldwide on sites of the Alzheimer associations. They provide digital information on dementia. The sites as well provide the possibility to chat with fellow patients and carers. The website Alzheimer Europe provides prevalence figures and research information. Both examples provide information on practical, social and emotional consequences of the disease in daily life. Alzheimer 'Your local branch' can be found in the UK and offers addresses of available services in your region. 'Carefinder' offers personalized interactive advice for patients and carers. The last site offers general information and helpful tips.
Information on service offerings	<a href="http://www.kiesmetzorg.nl">www.kiesmetzorg.nl</a> <a href="http://www.ZorgPortaal.nl">www.ZorgPortaal.nl</a> <a href="http://www.meetwente.nl/index.php/pagina/content/actie/uitgebreidzoeken/naam/zoeken_uitgebreid.htm">http://www.meetwente.nl/index.php/pagina/content/actie/uitgebreidzoeken/naam/zoeken_uitgebreid.htm</a>	These sites inform about available service offerings per region or nationally.
Information on legal and financial issues	<a href="http://www.2zw.nl">www.2zw.nl</a> <a href="http://www.rechtenregel.nl/">http://www.rechtenregel.nl/</a> <a href="http://www.gezondheidshulp.nl/">http://www.gezondheidshulp.nl/</a> <a href="http://www.socialezekerheid.nl/">http://www.socialezekerheid.nl/</a>	Information on legal and financial issues on care and support services cannot yet be found in one interactive, digital place. The website 2ZW offers general information regarding legal and financial issues. Users can select the topic that resembles their information need and find general information. Personal questions will not be answered. Several topics are available.
Compensation for disabilities for dementia patients	Electronic devices	ICT compensation for disabilities such as memory problems is a research area that has been explored by means of Electronic Memory Aids (EMA). Szymkowiak et al (2004) developed a PDA with mobile phone which is able to remind people in a multi model way, using sound, images or vibrations. Reminders can as well be remotely configured, for instance by the informal carer. Acknowledgement of the reminder can be sent back to the informal carer. The system enables people with mild to moderate dementia to remain relatively independent. Oriani et al (2003) report positive effects of an electronic prospective memory aid which can be pre programmed with vocal recordings and is able to remind the patient verbally to tasks he or she is required to attend to. Szymkowiak et al (2004) found that all users appreciated to be reminded (Dröes et al 2004).

Security	Smart houses/ domotics	‘Smart houses’ is a term to describe electronic and computer controlled integration of many devices in the home. ‘Domotics’ is the term used to mean domicile and domestic technologies. ‘Smart housing’ for older and disabled has been and is being tested at different sites in Europe (Elger and Furugren 1998, Bonner 1998). The technology allows deliberate and automatic control, including door and window openers, curtains and blinds, heating, lighting, security devices including motion sensors and video surveillance, telephone and communication, water taps, cooker, bed warming. The monitoring of activities can be extended with daily health checks. An example is an instrumented toilet to measure heart rate, temperature and nutrition (Tamura et al 1998). The Farkirk Mobile Emergency Care Service (MECS) operated by the Housing and Social Care Service in the UK includes a passive alarm system for older people with dementia. The technology employed comprises smoke, gas, hypothermia, heat detectors door switches, door reminder devices, flood detectors and pressure pads connected to MECS. The system enables patients to live independently and their carers think the service prevents fire and major incidents. Monitoring people in their own home is a part of a preventative strategy (Curry 2002).
Information on personal condition, care appointments and planning	Current research activities	Information on personal condition, care appointments and care planning is not yet available as ICT solution. Several initiatives are aiming to accomplish the required technology to enable safe and secure options for internet communication regarding personal health related topics. Zorgportaal Almere, IZIT (ICT In health care in Twente) and NICTIZ (National organization for ICT in health care) work on development of portals where this need can be fulfilled. A project of IZIT is the ‘Regional Zorgportaal’. This project aims to teach and enable the patient to monitor his or her own health and by doing so diminish pressure on the health care system.
Medical advice and information	<a href="http://www.kwflachtadvies.nl">www.kwflachtadvies.nl</a> <a href="http://www.dokterdokter.nl">www.dokterdokter.nl</a> <a href="http://www.kiesmetzorg.nl">www.kiesmetzorg.nl</a>	These sites inform users’ whit health complaints. ‘Dokter, dokter’ can offer personalized, and reimbursed information.
Assistance for daily living patients	<a href="http://www.hi.se/templates/Page.aspx?id=820">http://www.hi.se/templates/Page.aspx?id=820</a> <a href="http://www.fortec.tuwien.ac.at/silcweb/silc_en/SILC.html">www.fortec.tuwien.ac.at/silcweb/silc_en/SILC.html</a>	Software to support decision making regarding household activities and participating in social life, communication and performing vocational tasks. Telematics Application Supporting Cognition (TASC) system supports patients and can achieve increased independence, increased self esteem and improved social contacts. Operates via a PC. Supporting Independently Living Citizens (SILC) is an intelligent wrist worn life signs monitoring alarm system to increase safety and independence. The watch monitors well- being and two way conversations are possible. The watches possibilities can be customized to users’ needs. Operates via PC service center (Dröes et al 2005).

Table 8: ICT examples

### 3.2 'DEM- DISC'

Dementia care encompasses several problems in variation, fragmentation and continuous changing of care and welfare services. A variety of latent and manifest subjective needs and unmet needs of dementia patients and informal carers exist with regard to information. There is a need to create a continuum of flexible care and welfare service bundles in every region of the Netherlands attuned to needs of carers and patients. The expected growth of the number of dementia patients due to the proportional increase of the ageing population and subsequent growth of demand for care. As a response to these problems FrUX' s health care pilots aim is to explore opportunities for we-centric, context sensitive service bundles and to develop new innovative (mobile) services to support patients, informal carers and (semi-) professionals in dementia care. The idea of a Dynamic, Interactive, Social Chart for DEMentia care was therefore developed.

During the project time frame until March 2008 a prototype will be developed. 'DEM- DISC' will be designed to be accessible and enabled to provide information on care and welfare services. Information will respond dynamically to users' needs by providing context aware and customized bundles of care (figure 4).

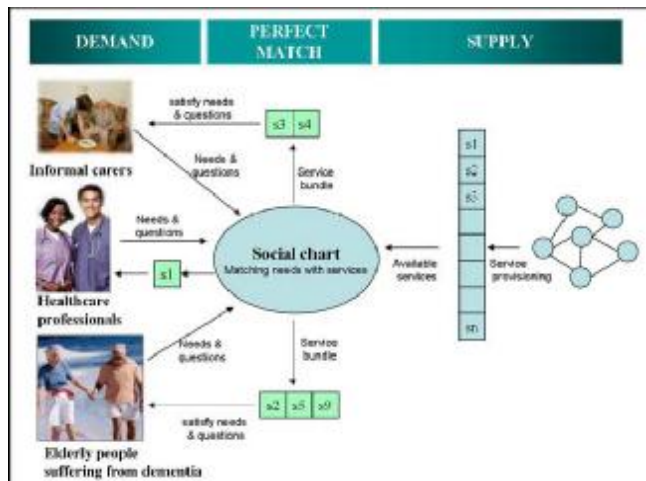


Figure 4: Dynamic matching of demand and supply

To enable users to find services to match their needs an interface<sup>1</sup> will help them to systematically clarify their demand for care. The ontology<sup>2</sup> is able to match demand and supply. The service ontology recognizes two perspectives, that of the user and the supplier. Since needs of users can be rather vague the needs are translated in needs, wants and demands (Kotler 1988). In Kotler's hierarchy one or more demands can satisfy a higher want or need. A need is a 'need' when mentioned as a state of felt deprivation, or a 'want' when mentioned as a expression of a need. A 'demand' is a wish for particular need one is willing to pay for in order to reduce the need. Needs, wants and demands are included in the resources of 'DEM- DISC's' ontology.

The supplier perspective is represented by a description of services they provide in terms of input resources they require. And in terms of outcome resources or benefits they supply. An example of an outcome resource is 'knowledge about behavioral changes' which is provided by the service 'informative meetings'. Besides these output resources qualitative attributes are described as well.

<sup>1</sup> The user interface is the aggregate of means by which users interact with a computer program or complex tool (the system). The user interface provides input; allowing users to manipulate the system and output; allowing the system to produce the effects of the users' manipulation (Wikipedia).

<sup>2</sup> An ontology is a formal conceptualization of a real world domain such that it has a computational representation that is fit for automated reasoning (Akkermans at al 2004).



Information can be provided during personal contact or in writing. The relations between all services are described in terms of service dependencies. By modeling supply and demand by means of this service ontology, it is possible to generate service bundles for a given set of customer demands (figure 5).

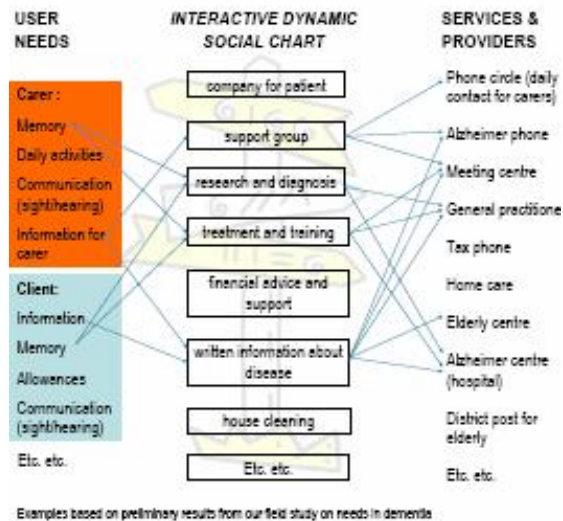


Figure 5: Operating procedure of the ontology

For each need a bundle of relevant services can be presented to the user. Service bundles are bundled services attuned to complex demands. The user is enabled to select a preferred provider. The engine is able to connect the interested user to the website of the provider of a particular service. Users will be enabled to base their preference for a service or provider on the information that will be presented by the website of the provider. The engine is able to connect the user to those websites. Providers are enabled to present the information in the way they prefer.

### 3.2.1 Use case

In order to explain functioning of 'DEM- DISC' use cases have been developed. The next case illustrates the role of 'DEM- DISC'.

Theo is worried about his wife, she is forgetful, disoriented at night and sometimes does not remember places. Her mother suffered from dementia. The husband remembers this and phones their general practitioner. He arranges an appointment and they are referred to a neurologist for a neurological examination. The neurologist diagnoses Alzheimer's disease. He tells them it is a degenerative disease that cannot be cured. He tells them about 'DEM- DISC' an interactive site that could help in finding answers to questions.

Later that week Theo looked at the 'DEM- DISC' site. The first question is how 'DEM- DISC' can be of help. Theo could select between two possibilities; looking for information or searching for an address. Theo chooses information. He is offered the possibility to enter his zip code, but it was not mandatory, instead of this option Theo selects his region in a map of the country. Now he sees a list of subjects from which he can choose. Theo chooses for information on how to deal with daily problems in the home. He makes this decision because he already knows about the disease from the period his mother in law suffered from Alzheimer's. The next question is if the information is for the patient or the informal carer. He chooses the option 'informal carer'. He sees a screen from which he can select from different topics (support, options for health care and welfare, adaptations in living environment, etc.). He chooses 'support' and is shown a list of available services, ranging from personal or group conversation to written materials. After selecting an option a list of providers who provide the service is shown. A button to show addresses nearby links him to websites of providers where he finds detailed information on topics

that will be discussed in an Alzheimer café close to their home. He finds information on the coming into existence of the Alzheimer café, what they intend to accomplish and who arranged for them. He reads they are not only meant to provide information, but also to meet other people in the same situation. He is enthusiastic and prints the information. He is happy with the site and grateful to the neurologist for mentioning the website. A few weeks later he visits the site together with his wife.

### **3.3 Reflection on ICT inventory**

The inventory of ICT applications in health care reveals that a variety of services exist. Several are currently in development. What can be found is an overview of nursing homes, static information on legal and financial issues, engines to find services when you are aware of your needs in professional terminology, directories and personalized advice after registration yourself and answering a questionnaire. Electronic devices and ICT applications to monitor health, create forms of ‘perceived’ safety and assist patients by enabling independent living.

‘DEM- DISC’ aims to improve accessibility by providing a single point of entry, enable users to find services for their specific needs, advise users about bundles of care and welfare services on their specific need based on which a preferred provider can be selected by the user. Services can be provided with or without entering personal data, based on the user’s preference.

A fully comparable or competitive service has not been found. ICT does seem adequate for provision of information, a need experienced by both patients and informal carers. The inventory of ICT applications revealed services are provided via different organizational arrangements. The central role is played by different parties, governments, commercial parties or interest groups.

### **3.4 Effects of ‘DEM-DISC’**

At a micro level ‘DEM-DISC’ operates to support people with dementia who live in the community, their informal carers and (semi-) professionals. On a meso level it operates to counteract the negative consequences of the fragmentation of services. Helping people with dementia to stay in their homes for a longer period of time can operate at macro level to contribute to a delay of nursing home admission and a reduction of health care expenditure (Dröes, R. M., Meiland, F. J. M., Doruff, S., Varodi, I., Akkermans, H., Baida, Z., Faber, E., Haaker, T., Moelaert, F., Kartseva, V., Tan, Y. F., 2005)<sup>3</sup>.

Implementation of ‘DEM- DISC’ will possibly lead to improved quality of life of persons with dementia and their carers, alleviation of carer tasks, transparency of service offerings, less fragmentation of care, a continuum of care and welfare services and efficient and customized service delivery.

Griffiths (2006) found reasons for Internet delivery of interventions which are also applicable for the concept of ‘DEM- DISC’ value proposition. The reasons are the unique advantages of the Internet technology, reducing costs and increasing convenience for users, reducing health costs, reaching isolated or stigmatized groups, timeliness of access to the Internet, need for user or supplier control of the intervention research related reasons. Many people are reached with just one mailing and easy storage of large amounts of information. Other advantages of the Internet are: reaching many people with one posting, easy storage of large amounts of information, ease of

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<sup>3</sup> [https://doc.telin.nl/dscgi/ds.py/Get/File-52013/presentatie\\_FRUX.ICMCC.DRÖES\\_etal.juni2005.pdf#search=%22opportunities%20for%20we%20centric%20service%20bundling%20in%20dementia%20care%2C%20Dröes%22](https://doc.telin.nl/dscgi/ds.py/Get/File-52013/presentatie_FRUX.ICMCC.DRÖES_etal.juni2005.pdf#search=%22opportunities%20for%20we%20centric%20service%20bundling%20in%20dementia%20care%2C%20Dröes%22)

updating information, providing personalized feedback and the possibilities for broadband and video transmission.

Reducing health care expenditure can possibly be reached by offering information which can result in timely interventions to prevent overburden of informal care. Information might just as well reach the opposite effect in a bad carer- cared for relation. In these situations information can result in a hastened institutionalization. An effect of support of informal carers can be that they realize the tasks are too burdensome for them (Pickard, 2004).

### **3.5 User perspective**

To assess how 'users' value web based delivery of information or interventions regarding long term care a literature study based on the work of diverse authors was conducted. Their work contains a number of useful guidelines or requirements for development of a viable business model for 'DEM- DISC'.

Kerr et al (2006) studied patient and care giver quality criteria and appreciation of Internet delivered interventions for long term conditions. Participants in the study generated criteria relating to information content, presentation, interactivity and trustworthiness. In relation to professionally generated criteria users' value ease of navigation in order to control which information is accessed and assistance with activities of daily living. This type of information does not have to be evidence based, rather based on personal experience of other users. Eysenbach (2002) found that the source of a website was an important feature in establishing credibility. He found that users say the source of the website is important in relevance to credibility of information. Participants told they look at the source, a professional design, a scientific or official touch, language and ease of use. In practice they do not check the 'about us' section. Kerr et al (2006) also found that the 'about us' section was hardly visited by users. They preferred instant recognition about the institution behind the site, rather than taking time to find out by themselves. Users also praised the absence of commercial sponsorship or advertisement and information on the frequency of updating of information to consider trustworthiness of a site. Fox and Rainie (2002) also found that strong commercial presence, out of date information and lack of clear referencing of information caused users to turn away. Kerr et al (2006) also found that not all users appreciate interactive components and online peer support. These features should be seen as an option that will address some users while others might prefer alternative facilities. Internet intervention with only one interactive facility will address only a proportion of potential users, while multiple interactive facilities are likely to appeal a wider range of users. Eysenbach (2002) found that participants value the Internet in order to assess the credibility of information compared to elsewhere, since information can easily be checked at other websites. Internet is valued to verify what a physician has told and look for alternatives, but as well they will verify what they found with their physician. A study in Netherlands on Internet use and health by Rijen (2005) found that women use the Internet significantly more often than men for questions regarding health. Internet is even used more frequently by men and women who are sick frequently or chronically (88% versus 73%).

The architecture of 'DEM-DISC' seems to meet some of the users' preferences in ease of navigation, control which information is accessed, assistance with activities of daily living, evidence based and based on personal experiences (future we- centric application).

In order to be able to offer the service to users a viable business model is required, which is the goal of this study. 'DEM-DISC' can be brought to users in several ways. There are a number of examples of ICT applications to inform persons with dementia and their informal carers. Remarkable is that these applications are provided via different organizational arrangements. The central role is played by different parties such as the government, commercial parties or interest

groups. Users prefer instant recognition about the institution behind the site and praise the absence of commercial sponsorship or advertisement. Chapter 5 will present the results of a study into viable business models.

## Chapter 4: Methodology and research approach

### Research design

The research goal is to design a viable business model for 'DEM- DISC'. Viability is assumed when both the users of the system and the providers of the system perceive sufficient value of their participation (Dröes et al 2004). There are no theories on how to approach development of business models in health care. Business modeling is considered an effective approach to assess value creation and assess market adoption possibilities. Business modeling in health care is a relatively new field in science. The main research question is: "Which organizational arrangements may lead to a viable business model for 'DEM- DISC'?"

The approach chosen is to conduct a study of organizational arrangements that may lead to viable business models for 'DEM-DISC'. Organizational arrangements are preliminary business models without detailed cost- benefit relations. The decision is based on the fact that health care is a regulated area, in which multiple interests play a role. Policies aim to find a balance between availability, accessibility and the preserve of untamed rise of expenditure on health care. Organizational arrangements create a tool to assess' opportunities for development of business models.

The organizational arrangements are based on the STOF model (Haaker et al 2004). The STOF model separates four fields within a business model; a service domain, a financial domain, an organization domain and a technology domain. The four fields combined should deliver network value and customer value. The 'service domain' and the 'technological domain' of 'DEM- DISC' are studied in other parts of the FrUX exploratory study. In this perspective these domains require less attention and the focus here is on the 'financial' and the 'organizational domain'. Arrangements are based on outcomes of a market analysis, a stakeholder analysis and an analysis of competitive or comparable offerings. Arrangements will be evaluated on viability in interviews and the 'best' model will be selected by conducting an Analytic Hierarchy Process.

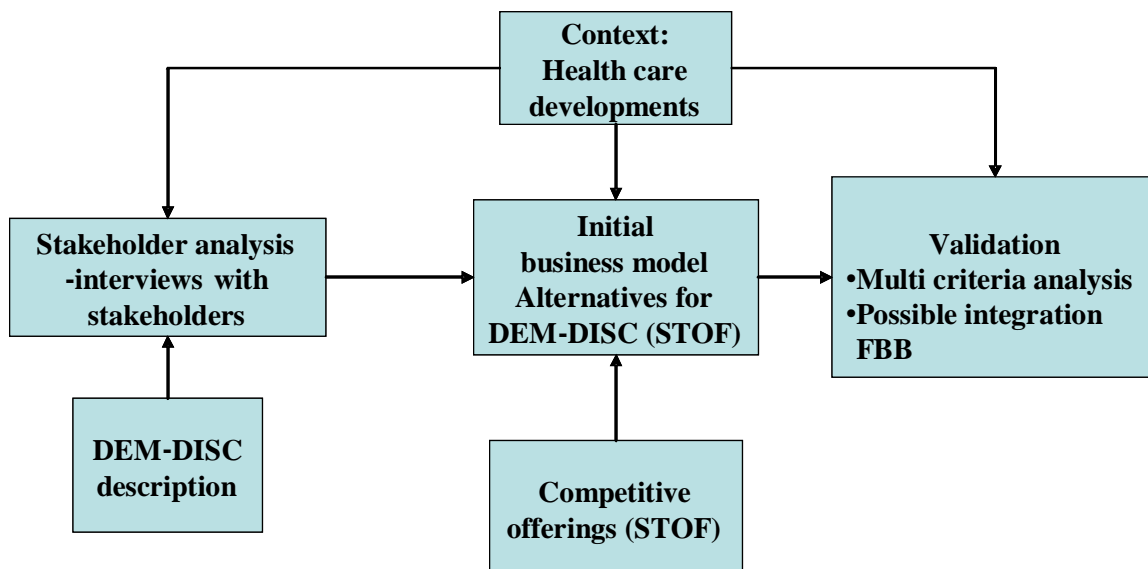


Figure 6: Study approach visualized

### **Preparation phase:**

The study was conducted from a health care perspective. The preparation phase began with conducting a market analysis, in which a study of legislation and orientation on chances and threats formed a central focus. The secondary aim was to identify or exclude the option of financing via the Dutch health care system.

The target of the stakeholder analysis is to assess for which parties ‘DEM- DISC’ may be beneficial and as a consequence will be relevant parties in a possible business model. A wide approach was used in the identification process. The analysis identified all types of care providers, interest groups, patient organizations, insurers, the medical profession, governments and employer organizations. The identified stakeholders were checked for completeness in discussion with three researchers in order to validate outcomes. The analysis was completed by describing the stakes of stakeholders, what should be delivered by them and what may be obtained by participating in ‘DEM- DISC’. Orienting on what may be obtained and delivered is part of the FBBM.

After the ‘stakeholders’ analysis an orientation on competitive (or comparable) service offerings was conducted. The goal was to investigate if a service like ‘DEM- DISC’ already existed and learn how other services are organized. ‘DEM- DISC’s’ competitive offerings were identified via the Internet. Results were checked on completeness by asking every participant of the interview which comparable or compatible offerings they know. All information on support of informal carers and dementia care was studied and placed in the STOF model (Haaker et al, 2004). This approach resulted in an impression of how other services were organized and financed. The subjects of this study were both organizations and interventions or ICT applications to support patients, informal carers and (semi-) professionals. Organizations were the Foundation Welfare Elderly (in Dutch: Welzijn Ouderen), Care offices (in Dutch: Zorgkantoor), Mezzo (interest group of informal carers), Point of Support Informal Carers (in Dutch: Steunpunt Mantelzorg), Service desk ‘Care’ (in Dutch: Zorgloket). An intervention was the project “Preventive Support of Informal Carers” (in Dutch: Preventieve Ondersteuning Mantelzorgers). Applications were the website [www.kiesmetzorg.nl](http://www.kiesmetzorg.nl) , a variety of online care- portals and the social chart of MEE Twente.

### **Research phase:**

Based on the study five organizational arrangements were constructed. Outcomes of a ‘DEM- DISC’ symposium (see: Hulstijn, J., Haaker, T., Huisman, E., Meiland, F., Slagter, R., 2005) were the principal on which three organizational arrangements were constructed after elaboration in correspondence with ‘DEM- DISC’s’ value proposition. Another organizational arrangement was derived from the market analyses. The last organizational arrangement steamed from the analysis of competitive offerings. In chronologic order:

- the ‘commercial model’
- the ‘insurer model’
- the ‘governmental model’
- the ‘community model’
- the ‘care providers’ model’.

The identified stakeholders were approached to participate in an interview. Interviews were free of obligation and results would be processed anonymous. In the interviews the interviewees ideas and opinions with regard to ‘DEM- DISC’s’ service concept, possible organizational arrangements and value proposition were discussed. A semi- structured interview protocol was used to conduct the interviews (Appendix C). Fourteen interviews were conducted. Each participant received a written report of the interview and was given two weeks to approve with the content of the report. In total 14 representatives of identified stakeholders were interviewed. Interviewed parties are:

1. Policymaker full chain provider (all types of intra- and extra mural care), Amsterdam
2. Director national government, the Hague
3. Policymaker health care insurer, Amsterdam
4. Manager and coordinator dementia, support for informal carers, Amsterdam (n=2)
5. Director home care, both Amsterdam and Twente
6. Care manger and controller, nursing homes and daycare, Enschede (n= 2)
7. Director national patient organization, Bunnik
8. Director meeting centers for dementia (daycare for patients and support informal carers), Amsterdam;
9. Director support for informal carers, manager NDP Twente, Enschede
10. Policy maker, support for elderly, Enschede.

Interviews were conducted at two sites, Amsterdam and Enschede. Amsterdam was chosen because Amsterdam is the location of the pilot in 2007. Enschede is a city where the IZIT study is being conducted. IZIT means ICT in health care in the Twente region. The region was selected to test possibilities of ICT solutions without having to comply with to current health care regulation. IZIT has different projects in which a wide range of health care providers, knowledge institutes and health care insurers cooperate. It is possible that as a result of this cooperation and the focus on ICT the idea of 'DEM- DISC' is more welcomed in this region. Furthermore a calculation model from TNO shows that the Twente region can expect the largest number of dementia patients. In Amsterdam influences of the increase of the ageing population and growth in the number of dementia patients are not expected until 2015.

Outcomes of the interviews were discussed in three expert interviews to assess if the interviews formed a representative sample for the health care area. Expert interviews are conducted to assess if the interview outcomes formed a representative example of the field of 'care'. Interviewed were:

- Manager health care insurer 'Cure', Twente
- Manager health care office department 'Clients and quality', Twente
- Manager organization for research and development of ICT in care and cure, Twente.

The outcomes of the expert interviews provided confirmation of interests, chances and threats stemming from the perspective of stakeholders.

### **Completion phase:**

Interview outcomes formed input for a Multi- Criteria Analysis (MCA). The Analytic Hierarchy Process (AHP) of Thomas Saaty (1980) was used to conduct the MCA. Expert Choice developed software to conduct the MCA in groups, called Team Expert Choice'. It is a decision support technique. Application of the technique requires selecting a goal and constructing a hierarchy of criteria. The goal is to select 'the best' business model for 'DEM- DISC' based on the research question. The hierarchy was constructed based on the interview outcomes and the FBBM (Haaker et al, 2004). Outcomes were classified in critical success- and design factors of the FBBM(table 12). The interviews were read and coded by two researchers of the FrUX project. To complete the construction of the model for the MCA alternatives are entered in the model. The participants' value their preference for the alternatives in pair wise comparisons based on the way the criteria are present in the four alternatives. An overall score will present the overall preference for one of the alternatives. Within the conducted methodology the outcome can be considered an experiment in facilitating business modelling. An additional aim in the FrUX project is to develop a method for business model development in health care. The aim is to elaborate the FBB methodology. The methodology in this thesis could be a directive for elaboration.

The AHP was conducted with two of the identified and interviewed stakeholders.

- Director support for informal carers, manager NDP Twente, Enschede
- Policy maker, support for the elderly, Enschede.



## Chapter 5: Theoretical framework

### 5.1 Value creation in 'E- Business'

'E- Business' is business conducted over the Internet. 'E- Business' is dynamic, rapidly growing and highly competitive characteristics. These promise new avenues for creation of wealth (Amit and Zott, 2001).

Companies that use the Internet to increase transaction efficiency have the potential to create value for all parties involved:

- Strengthen the supply chain by reducing supplier costs and integrating vertically;
- Provide a large array of products and services;
- Make the transaction convenient for the consumer;
- Allow the consumer to save time;
- Reduce the asymmetry of information amongst parties.

A strategy for value creation in 'e- business' is the web's ability to draw and retain customers, which is called 'stickiness' by Zott and Donlevy (2000).

- Reward customers for their loyalty;
- Personalize the product or customize the service;
- Build virtual communities;
- Establish their reputation for trust in the transaction.

Amit and Zott (2001) found that value of 'e- business' is created by four interdependent dimensions; efficiency, novelty, complementarities and lock- in. These four 'value drivers' are anchored in entrepreneurship and strategic management theory and enhance value creation of e-business. No single entrepreneurship or strategic management theory can fully explain value creation; integration of theoretical perspectives in the business model construct can construct a unit of analysis that captures value creation arising from multiple sources. A business model depicts the design of transaction content, structure and governance. Value is created by exploitation of the business opportunities and forms a locus of innovation for the firm, its suppliers, partners and customers. Value refers to the total value created. No distinction between the beneficial parties of value, the firm, the customer, or any other is made. Brandenburger and Stuart's (1996) view the total of value created as the sum of values appropriated by each party involved in a transaction. Amit and Zott extend this view by positing that total value created through a business model equals the sum of the values appropriated by all participants in a business model and over all transactions enabled by the business model.

Figure 7 visualizes the creation of value according to Amot and Zott (2001) by 'value drivers'

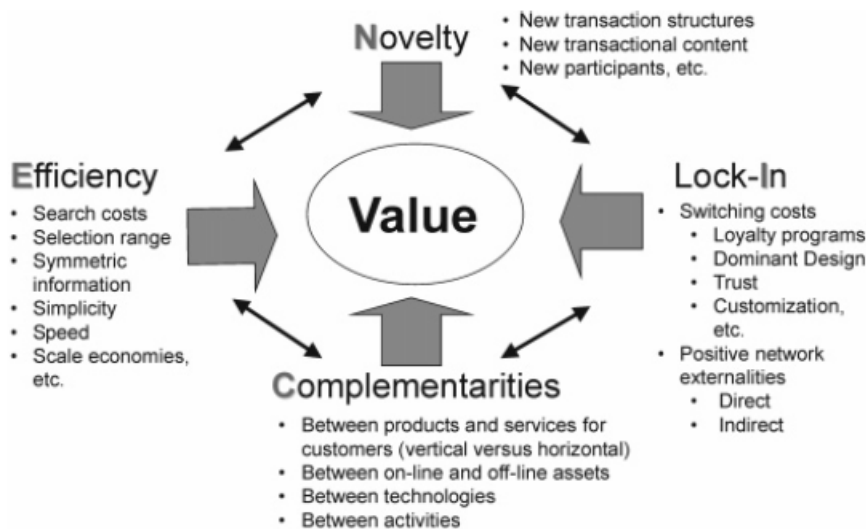


Figure 7 derived from Amit and Zott (2001)

### 5. 1. 2 What is a business model?

Based on Amitt and Zott’s recommendation value creation should be conducted within a business model it is relevant to assess what a business model is. This section will explain the concept of a business model.

Chesbrough and Rosenbloom state the concept business model is widely used, but rarely well defined (Brainscomb, 2001). Sometimes the term business model is reserved for only one company and describes in the business model the role of that company in its environment. Other visions are that a business model is a model of profits, and the concept of generating these profits is considered to be the business model. These last visions do not describe the cooperation in networks or chains that might be required in order to create customer value (Haaker et al, 2004).

Two approaches will be described, first the STOF model (Haaker et al 2004) and second Chesbrough’s view (2003). The first three paragraphs describe the STOF model in which definitions of Chesbrough are introduced. The fourth paragraph explains Chesbrough’s view on business modeling.

Haaker, Faber and Bouwman (2006) wrote: “The field of business models has developed over the past few years from defining business models (Afuah and Tucci, 2001, Bouwman and Van der Ham, 2003, Hedman and Kalling, 2003, Mahadevan, 2000, Osterwalder and Pigneur, 2002, Timmers, 1998, Weill and Vitale, 2001, Chen and Nath, 2004) via exploring business model components into categories, to developing descriptive models of business models (see for an overview: Pateli and Giaglis, 2003). The majority of researchers focus on actors, relationships, and value objects exchanged (see e.g. Weill and Viatel, 2001, Tapscott, Lowi and Ticoll, 2000).”

Haaker, Faber and Bouwman focus on business models for service offerings which require cross-company or multi- actor collaboration. A business model is considered a networked enterprise: “A collaborative effort of multiple companies to offer a joint proposition to consumers” (Haaker et al, 2006). Within the Freeband program the STOF model was developed by researchers from the Telematica Institute and TU Delft (Haaker et al 2004). From their perspective a business model can be seen as a blueprint for interrelated components; service offering, technical architecture, organizational and financial arrangements. It describes how in a chain or network customer value and network value will be created. A business model is a blueprint that describes how a network of organizations co- operates in creating and capturing value from new, innovative services or products (Chesbrough and Rosenbloom 2002).

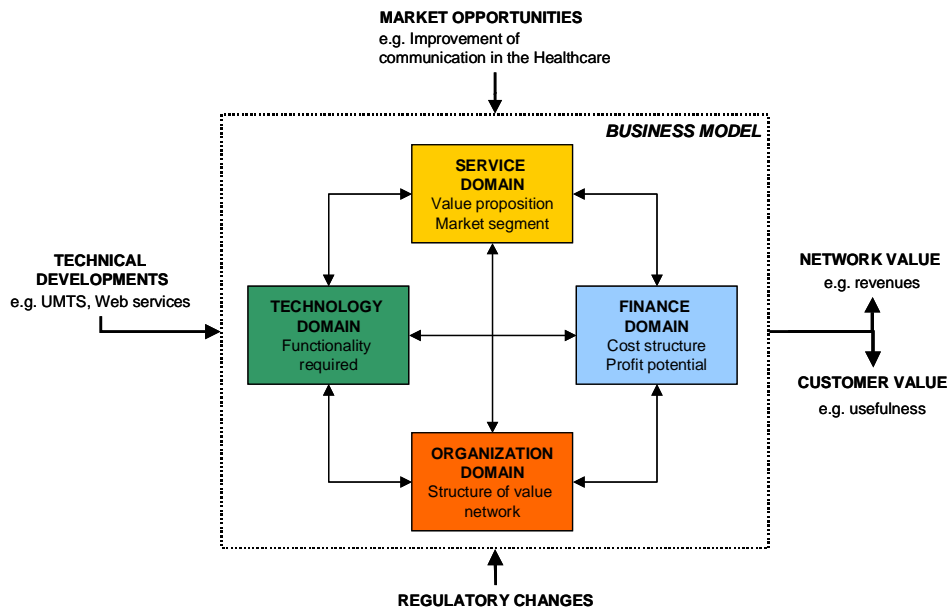


Figure 8: STOF model (Haaker et al, 2004)

The ‘service domain’ is defined as: “a description of the value proposition (added value or a service) and the market segment at which the service is targeted”. The ‘technology domains’ definition is: “a description of a technical functionality required to realize the service”.

The definition of the ‘organizational domain’ is: “a description of the structure of the multi actor value network required to create and distribute the service and to describe the focal firm’s position in the value network”. The ‘finance domain’ is: “a description of the way a value network intends to generate revenues from a particular service and of the way risks, investments and revenues are divided among the various actors within the network”. The domains need to be balanced to create sufficient economic and customer value (Haaker et al 2004).

Chesbrough and Rosenbloom (2002) state the business model provides a coherent framework that takes technological characteristics and potentials as inputs, and converts them through customers and markets into economic outputs (figure 9). The business model is thus conceived as a focusing device that mediates between technology development and economic value creation. A business model integrates a variety of academic and functional disciplines. They use six functions while referring to a business model:

1. Identify a market segment, that is, the users to whom the technology is useful and for what purpose;
2. Articulate the value proposition, that is the value created for users by the offering based on technology;
3. Define the structure of the value chain, that is the network of activities within the firm required to create and distribute the products or services offered to customers;
4. Estimate the cost structure and profit potential of producing the offering, given the value proposition and value chain structure chosen;
5. Describe the position of the firm within the value network linking suppliers and customers, including identification of potential complementors and competitors;
6. Formulate the competitive strategy by which the innovating firm will gain and hold advantage over rivals.

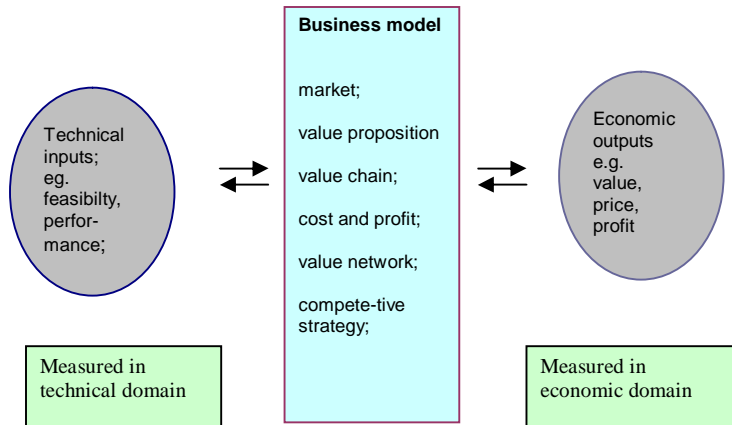


Figure 9: Mediation of a business model between technological and economic domains. Figure is derived from Chesbrough and Rosenbloom (2002).

Both Chesbrough and Rosenbloom (2002) and the STOF model (Haaker et al, 2004) adopt the view that a business model is a blueprint that describes how a network of organizations co-operates in creating and capturing value from new innovative services or products (Haaker, Faber and Bouwman, 2006).

## 5. 2 Freeband Business Blueprint Method (FBBM)

The FBBM can be applied to develop a business model for innovative mobile ICT services. The method describes how to build a business model step by step and stems from the STOF model. The methodology is useful in early stages of innovation. It enables actors to explore and contemplate different ideas and options i.e. the process of innovation is modeled as subsequent phases and iterations. Each phase consists of divergent and a convergent part. By applying insights from creative techniques like brainstorming and boundary examination the FBBM sessions facilitate the generation, choosing and detailing of ideas. The approach is based on the STOF model and consists of three steps.

1. Quick scan: A rough sketch model is made by actors by answering questions with respect to the four domains.
2. Critical Success Factors (CSF's): The potential success of the rough sketch can be tested against six critical success factors (Appendix D). The evaluation on the success factors determines which parts of the business model need to be elaborated. Success factors were derived from extensive research and a large number of case studies. The factors are vital in creating sufficient economic and customer value.
3. Critical Design Issues (CDI's): The necessary elaboration can be detailed by critical design issues (Appendix D). Critical design issues follow from the success factors and feed the design choices. Involved actors should attune the design choices and strategic interests. Balancing requirements and strategic interests is vitally important.

The process is visualized in figure 10. Steps II and III may lead to changes in the original business model design or cancellation of the project. In conducting an iterative process both steps may be repeated.

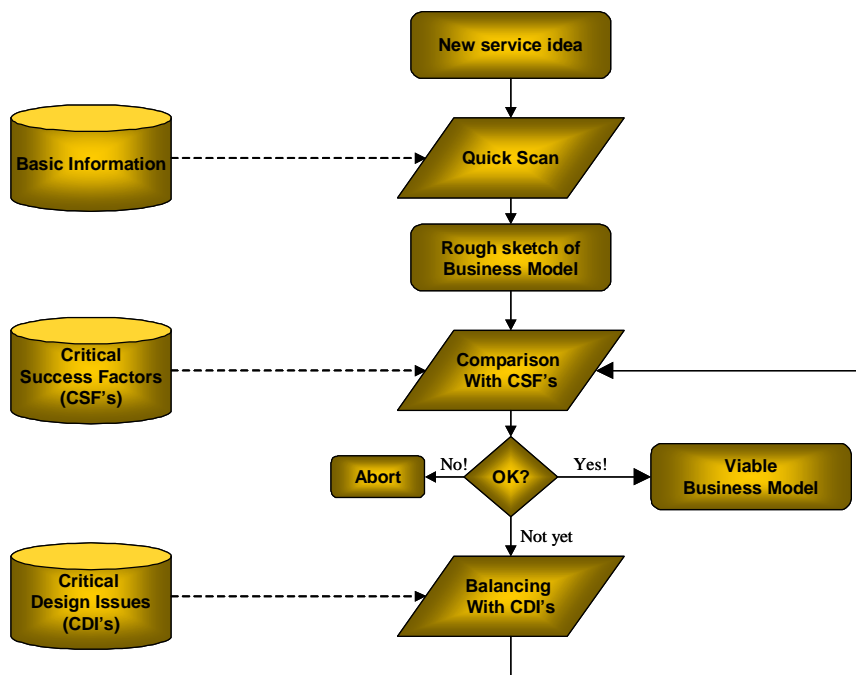


Figure 10: FBBM Process

### 5. 3 Analytic Hierarchy Process (AHP)

Health care is an area of multiple interests (patients, families, insurers, government, care providers, working population, etc.). The Analytic Hierarchy Process (AHP) is well applicable because it enables to consider all diverging interests in a comprehensible way. The STOF model was applied because it enables the structuring of the basics of a business model. The theories together construct a methodological approach that respects all divergent interests. In the perspective of this study to design a viable business model it is especially appreciable that interests of absent parties can be represented by applying the AHP. It attributes to the goal to design a viable business model.

The AHP is developed by Saaty (1980). The technique is designed for multi criteria decision analysis. It aims to support complex decisions. When a decision has to be based with regard to multiple aspects the human mind is no longer capable of overseeing all aspects. This technique enables users to build a hierarchy with all relevant criteria and eventually sub criteria. Criteria can either be quantitative or qualitative or both. By using the hierarchy one can judge how well the alternative fits the goal.

The technique can be applied individually or in groups. The first step is to select a goal. The second step is to construct a hierarchy of criteria. To each criterion a relative weight will be assigned by pair wise comparisons to represent importance of the criterion compared to the other criteria. Last step of constructing the model is to add the alternatives. After completing the model pair wise comparisons will result in preferences for the alternatives with respect to a criterion. An overall score will calculate the most preferred alternative with respect to the goal.

An example is appropriate to explain the methodology of AHP. In this simplified example the goal is to select the best car. The buyer decides that: safety, performance and price are the criteria on which the new car should be chosen. He has a preference for two cars, these are the alternatives.

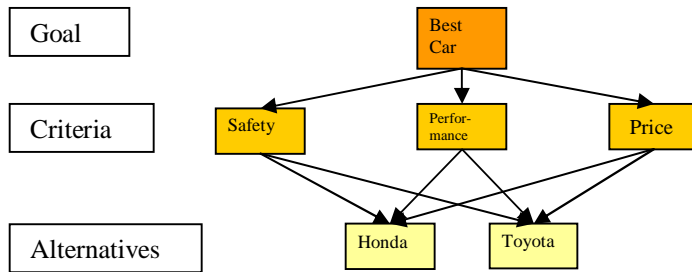


Figure 11: Hierarchy for the Analytic Hierarchy Process to select a car out of 2 alternatives based on three criteria.

The first step is to estimate the weights of the criteria; one estimates the relative importance of one criterion to another with respect to the goal. For instance safety is most important. This quantification is derived from a matrix of pair wise comparisons between two criteria. The relative preference is based on an ordinal scale ranging from 1 to 9:

Value	Meaning
1:	Equally
3:	Moderately
5:	Strongly
7:	Very strongly
9:	Extremely
2, 4, 6, 8:	Intermediate values

The next step is to value how the criteria are represented in the alternatives. Expert Choice designed software to conduct an AHP which offers three options to value criteria; a numerical, a verbal and a visual. With all three methods the priorities of the alternatives are computed. The difference is how the figures are assigned to the preferences; even with the visual method priorities are computed.

The question that is posed is: With respect to safety: the Honda is (computed priority) more preferable than the Toyota.

Honda	9 8 7 6 5 4 3 2 1 2 3 4 5 6 7 8 9 *-*-*-*-*-*-*-*-*-*-*-*-*-*-*	Toyota
-------	--	--------

After computing priorities for each criterion regarding the preference of them to the alternatives an overall preference can be calculated. This is the answer on the goal: ‘selecting the best car’.

The AHP provides an inconsistency ratio. This inconsistency ratio (C. R.) rises if there are more inconsistencies. Measurement is based on maximum eigenvalue of the matrix of pair wise comparison. This inconsistency should never be larger than 0.1 (C.R. ≤ 0.1). A higher C. R. indicates that contradictory priorities have been computed. If so, one should return to the pair wise comparison and reconsider the assigned priority. Especially when the AHP is applied in groups this measurement forms an occasion to reconsider assigned priorities. Columns of the matrix are filled with the aggregated pair wise comparisons as computed by the geometric mean.

The group should discuss the reason why the individual values were assigned; these values can be visualized for all participants by the software. During the process of the discussion a degree of consensus will be achieved. In this perspective applying the AHP seems to be a contribution to designing business models in health care.

## 5.4 Organizational arrangements

Based on preliminary results 5 organizational arrangements have been developed. These organizational arrangements may have the potential to result in viable business models. The arrangements are not complete business models, since they lack detailed cost- benefit relations. The likelihood of viability and desirability of the arrangements will be discussed in interviews. Outcomes of the interviews will form the input for the multi criteria analysis. The MCA will function as a technique to select the best model in which all interests of relevant participants are present.

The basis for development of organizational arrangements is based on required roles. The first aspect is the need for information on available services. In order to inform users ‘DEM- DISC’s’ engine should be filled with services. Care providers should deliver information on their services. Furthermore a party has to deliver general information with respect to dementia, preferably an independent party with ‘up- to date’ knowledge. One could think of a research institute. Another relevant party is a financing party. This party should deliver financial means from which ‘DEM-DISC’ can be managed. Sponsors and advertisers could be included in order to diminish expenses by creating extra income stemming from ads or sponsorship. ‘DEM-DISC’s’ provider is the manager of the system. The providers’ duty will be maintenance of the system and included data. This duty could be fulfilled by a domain expert<sup>4</sup>. Finally ‘users’ are required. Their role is to use the system in order to find personalized information to match their needs.

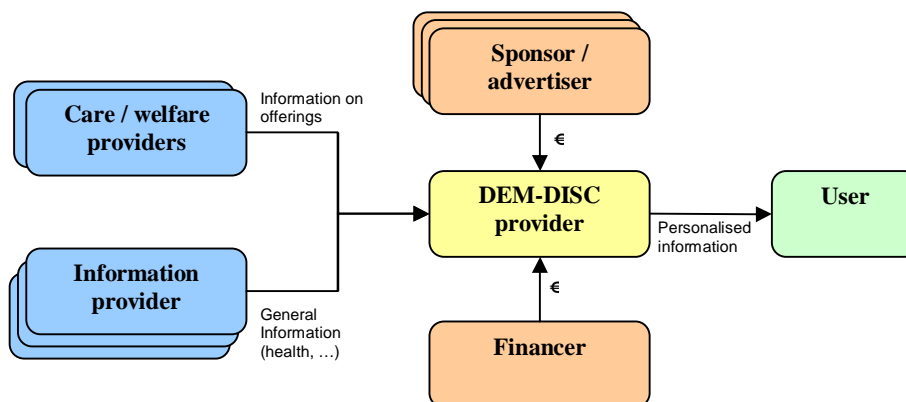


Figure 12: Required roles in a ‘viable’ business model for ‘DEM- DISC’

Five organizational arrangements are developed:

- Commercial model
- Providers model
- Governmental model
- Community model
- Insurer model.

<sup>4</sup> A domain expert is a person with knowledge or skills in a particular area. Domain experts display information in a logical fashion to code it into a computer system by which it is made available for ease of use by end users. They are specialized in the creation of and maintenance of expert systems (Wikipedia).

### 5.4.1 Commercial model



The commercial organizational model is based on the principal that financial or intangible benefits are generated by offering the service to end users. Several scenarios are imaginable to fulfill this goal. The options can be applied individually or in combination.

First option: ‘DEM- DISC’ is offered by a commercial party, for instance a pharmaceutical firm. The pharmaceutical firm pays for management of ‘DEM- DISC’ and the contacts with users deliver intangible benefits. The firm is enabled to create a channel which potentially creates users’ trust in the firm and its products. In the Netherlands Roche offers the website: [www.Overgewicht.nl](http://www.Overgewicht.nl) which advises users how to loose weight. The user fills in a questionnaire. One question is whether or not the drug that helps them to lose weight and create long term health benefits has been prescribed by their general practitioner. In the United States Novartis offers the website: <https://www.alzheimersdisease.com/index.jsp>. It contains information for both patients and carers. The interface provides users the chance to read about Exelon, a drug that Novartis produces to slow the process of dementia.

Second option: Users are enabled to find relevant service offerings to fulfill their needs. Within ‘DEM- DISC’ users themselves select a preferred provider and contact a provider of choice. If ‘DEM- DISC’s’ provider would connect provider and client it is a possibility that fees would be charged to the care providers. This form can be found at [www.independender.nl](http://www.independender.nl) where consumers are informed with respect to insurances. After closing an agreement for insurance, the insurance company pays a fee to Independender.

Third option: A provider of ‘DEM-DISC’ is able to generate information by offering the service. For example user preferences with regard to Internet use by the target group, preferences for services and gaps in service offering. This information is valuable and can be sold. Preferred relations would increase the value of the information, because if information would be sold to every provider, it would lose its value. An example is Mediquest.

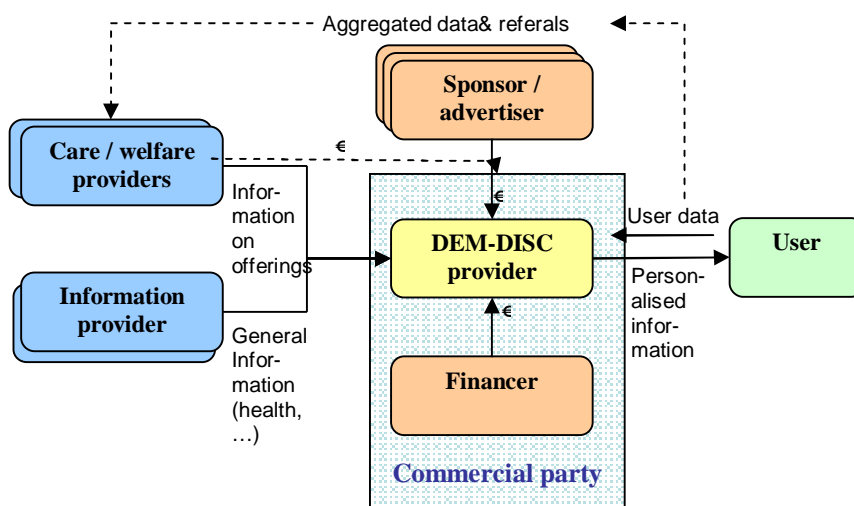


Figure 13: ‘Commercial’ organizational arrangement



## 5. 4. 2 ‘Care providers’ model



The providers’ model comprehends the idea the service will be provided by a network of care providers. The cooperation presents the possibility to reach their target group and inform them over relevant services from their product ranges. The information could bring in customers. The cooperation can stem from existing co operations like SIGRA (Samenwerkende Instellingen Gezondheidszorg Regio Amsterdam), regional departments of the National Dementia Programs or co operations like within the IZIT (ICT en Zorg in Twente) project in Twente. On the Internet one finds ‘care-portals’ in which services, addresses and information are offered. Those kinds of cooperation could be the network from which the service is offered. Costs for offering the service should be shared within the network, possibly reduced by ads or sponsorship.

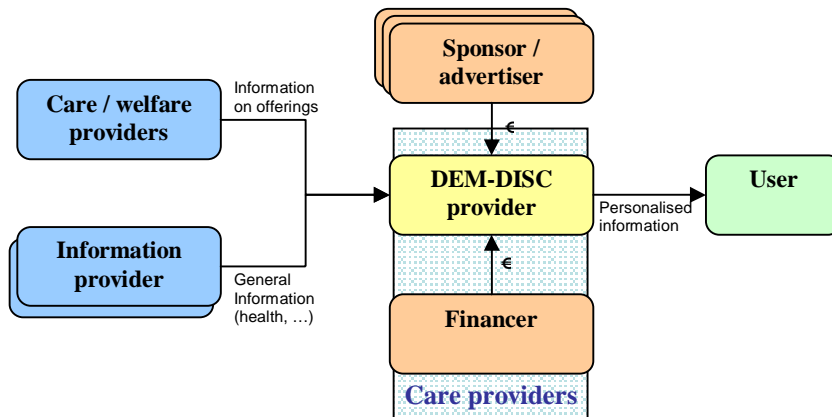


Figure 14: ‘care providers’ organizational arrangement

## 5. 4. 3 The Governmental model

The idea for the government model stems from available and increasing budgets for support of informal care. Ads and or sponsorship are not likely to be based on assumptions of conflict of interest. The governments’ interest is based on the expected increase in the number of patients due to the proportional increase of the ageing population.



The model holds three options for different scales. An option is the national scale; the national government pays for the exploitation of the service, comparable to [www.kiesbeter.nl](http://www.kiesbeter.nl) and [www.zorgvoorbeter.nl](http://www.zorgvoorbeter.nl) and [www.2zw.nl](http://www.2zw.nl). These three websites provide information available to users and are paid for by funds provided by the government. Another possibility is a regional scale; the Provincial authorities offer the service for the inhabitants. The interest of the authorities can be assumed on the basis of financial contributions made to the regional NDP’s. Lastly, the local option; the local authorities offer the service. This form is comparable with the ‘Zorgloket’ which is offered by local authorities to their citizens as entry point for care. Stemming from the introduction of the Societal Support Act (WMO) development of these offices was accelerated.

The 'Zorgketten' are staffed by clerks and are accessible online. 'DEM- DISC' could be included in the current form and expand knowledge of clerks and be available for patients, informal carers and (semi-) professionals.

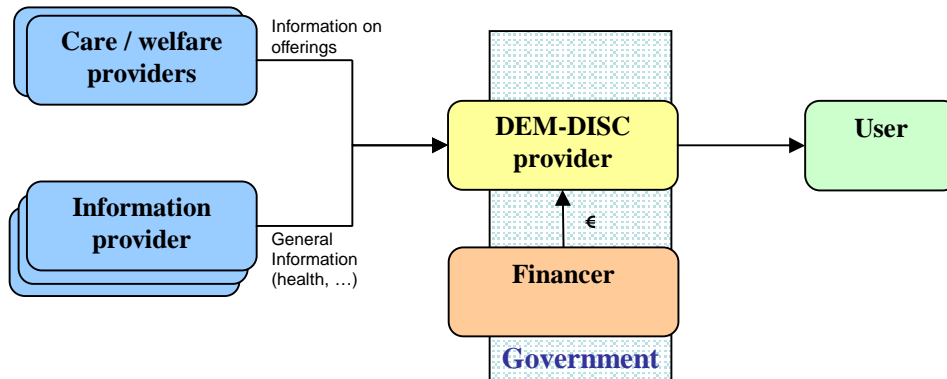


Figure 15: 'Governmental' organizational arrangement

#### 5. 4. 4 The 'community' model

The community model is based on management stemming from interest groups. These could be patient organizations or interest groups for informal carers. In general their aim is to inform and 'empower' the parties concerned. These types of organizations comply with regulation with regard to sponsors or ads. For example a patient organization for persons with dementia does not allow ties with pharmaceutical firms. Ads from newspapers or magazines will be allowed, and make sense since target groups of publishers can be found within the user group of the service. Sponsorship could be possible from organizations for the elderly or companies that win intangible benefits by sponsorship (e.g. positive attention). Cost should be carried by the organization.

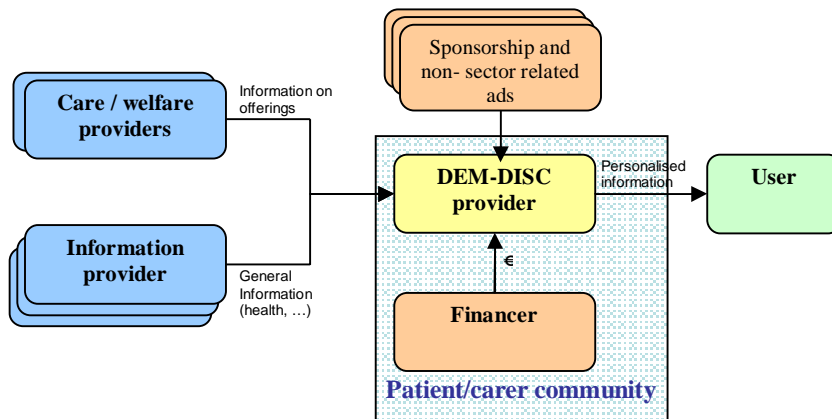


Figure 16: 'Community' organizational arrangement



Your local branch

#### 4. 4. 5 The Insurer model

An insurer could offer the service to its insured persons and distinguish itself by competition with other insurance companies. The orientation on one patient group might attract new clients and reduce expenditure on health care cost for informal carers, since overburden can possibly be prevented. The insurance company pays for management and cost can possibly be diminished by ads or sponsorship. Within 'cure' one witness's chain orientations from where savings are achieved by preventing health complications. Specialization in patient groups can then be made visible to the public. An example is 'AGIS DIAGIS' from the Agis insurance company. The

‘AGIS DIAGIS’ program is specialized in creating health profits for diabetic patients and reduces expenditure. The idea that stems from the program that it is wise for diabetics to be insured by Agis ([www.Agis.nl](http://www.Agis.nl)). Another example of creating good-will is provided by Menzis, also a health care insurance company which compensates insured persons for expenses made for substitute care when the informal carers themselves are not able to look after those they care for to because they themselves are sick.

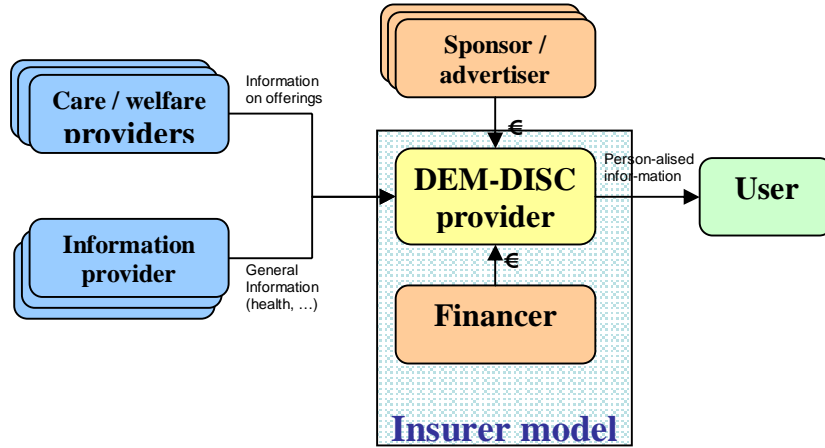


Figure 17: The ‘Insurer’ organizational arrangement

## Chapter 6: Results of data analysis

In ‘Results of data analysis’ the outcomes of the interviews and the outcomes of the Analytic Hierarchy Process (AHP) will be presented. Interviews were conducted to study stakeholders’ thoughts and opinions with regard to ‘DEM- DISC’ and the organizational arrangements. First a general impression will be described and subsequently outcomes will be classified in groups presented in a summary as well as a in tables. Then the expert interviews will be described and the last sections provide the AHP outcomes.

There were no interviewed stakeholders who denied the need for a service like ‘DEM- DISC’. One stakeholder with some foreknowledge about ‘DEM-DISC’s’ service concept was disappointed about the characteristics of the service. In his mind the patients’ need would be the starting point, based upon which providers would develop and offer services. He thought the system would operate in a way that is comparable to the intended functioning of the AZR (AWBZ Zorgbrede Registratie) which is under construction. In the data base all CIZ indications are registered and trends can be discovered, based on which services and availability could be adapted to needs by the health care offices. This particular stakeholder questioned the demand driven character of the system. The other interviews revealed no more critiques.

In general it seems that the earlier in the process of dementia a stakeholder plays a role for the patient and, or the informal carer, the more ‘DEM-DISC’s’ concept was valued. A provider of intramural care (6) told that his service is always found, since the service is meant for the final life stages of the patients. On average patients stay in a nursing home for two years and care provision is discontinued because patients decease. This stakeholder still values the service concept since it enables informal carers to maintain a manageable home situation for extended periods of time. It is imaginable that the delivered network value is higher for the stakeholders who play a role earlier in the process.

### Classification of outcomes

All identified stakeholders who participated to the interviews commented on the organizational arrangements. These comments revealed relevant factors on which participation in the value network will be based. The comments contributed to the assessment of likelihood of organizational arrangements. Interviews will be presented in tables and participants will be numbered, by which answers are traceable to type of organization and function.

TABLE	CONTENT	QUESTIONS
9	General opinion with respect to ‘DEM-DISC’s’ service concept	Question 1,..., 6 Interview protocol included in Appendix C
10	Comments on organizational arrangements	Question 10 Interview protocol included in Appendix C
11	Value proposition based on participants’ participation in value network	Questions 11, ..., 14 Interview protocol included in Appendix C
12	Construction of Hierarchy for AHP based on interview outcomes	Full interview Interview protocol included in Appendix C

### General opinion with respect to ‘DEM- DISC’s’ service concept :

Table 9 explains how participants think about the need for ‘DEM- DISC’ and on what grounds they base their opinion, what the value proposition of the system will be and to whom. The final question is if they are familiar with comparable or competitive offerings and differences between ‘DEM- DISC’ and those services. All participants were convinced the need for a service like ‘DEM- DISC’ exists. The value will be the systems capability to create the ability to find services, which will be valuable for patients and informal carers. The concept of ‘social charts’ is

emerging based on the examples of comparable offerings mentioned by participants. 'DEM-DISC' distinguishes itself by needs clarification and technique and considered to contribute to 'empowerment' of patients.

### **Comments on organizational arrangements:**

Table 10 reveals reactions to the possible models. Organization stemming from either the 'community model' or the 'governmental model' is considered most likely. 'Providers' model' seems to be an acceptable option for most participants, although the fear of competition threatens this model. The 'commercial model' is appreciated based on possibilities with regard to the cost-benefit relation, fear of biased information and position of the patients' are con-arguments.

The 'insurer model' was discarded based upon comments stemming from the interviews (table 10). The 'insurer model' is discarded because financing structure in health care (separation 'care' and 'cure') does not make this organizational arrangement very likely. The model is seen as a future possibility when 'care' and 'cure' will be integrated.

With regard to the 'governmental model' some discussion was found. The model at regional level would perhaps not be as likely in every region, based on differences in policies of the Province. The local model would also encounter differences between cities and their authorities. As a consequence of the introduction of the Societal Support Act authorities developed policies to obey the framework formulated by the national government. Especially with respect to online information some authorities developed their local services within "Vraagwijzer" or "Zorgloket" formats. These formats are available on line to citizens and assist clerks in their job to advice visitors who visit their authorities. It does not seem likely that two systems will be employed. Hence the model should not be excluded based on this argument. Furthermore a strict local orientation is not a desired scale, because not all services are locally available and traveling might be required. Data should be withdrawn from 'DEM-DISC's' regional orientation. The national model does not have the governments' preference since the NDP has been developed to offer the regions a process in which responsibilities are placed lower in the hierarchy. It functions as a test to see whether this approach results in improvements in care that are not initiated by the national government. Limitations stemming from local and regional differences are acknowledged. The governmental model was not deleted since policies do not exclude the possibility and examples of this model exist in other areas.

### **Value proposition based on participants' participation in value network:**

Table 11 reveals what interviewed parties themselves think to gain by participating (added value, source of revenue and indirect revenues). Added value is the information provided by the system for both users and providers and brand awareness. Sources of revenue are potential new clients and expansion of knowledge for employees. Indirect revenue is that the overview is applicable for development of new products and useful in preparation for tender procedures. In the row 'specific contribution' it will be mentioned which roles cannot be missed in order to offer the service, or which roles are missed and should be included. With respect to this question presence of a consumer- or patient party is appreciated, inclusion of soft-data on which consumers base their choice and information on prevention of dementia. One participant would like to use the system on PDA's by which nurses are enabled to advise clients and create independence by empowering patients. The last row describes participants' opinion with respect to 'DEM-DISC'. The question was posed as one of the last questions of the interview. Participants are more familiar with the service offer and value proposition for both users and themselves. It can be concluded there is a remaining enthusiasm, even when providers win very little by participation based on their product ranges. One participant questions the demand driven character, he does not deny the need for a system to enable users to find adequate services.

**Construction of Hierarchy for AHP based on interview outcomes:**

The comments from participants of the interviews also formed input for constructing the hierarchy for the AHP. Interviews were read and coded by two researchers. The aim for coding was to summarize the interviews and make outcomes applicable for constructing a hierarchy. Coding was done within the FBBM's terminology of critical success- and design issues. Table 12 shows which comments form the basis for the terminology for the construction of the hierarchy. Comments are traceable to type of organization of the participant.

Before applying the hierarchy for the AHP the argumentation was discussed with participants of the AHP. They could enter or delete criteria. Participants to the AHP agreed with the hierarchy.

Table 9	Need for 'DEM-DISC'?	Based on what grounds?	Value proposition?	Customer group?	Complementary products?	Difference?	Your services included?
1	For informal carers	Availability of information is important	Fulfill need for information where to find services	Informal carers and in future patients	Social chart SIGRA		Yes, do not expect to win many new clients
2	Seems necessary	Market imperfections	Producers enabled to cooperate and experience gains stemming from cooperation	Channel to all clients			Not applicable
3	There is a need for such a service, not convinced it should be 'DEM-DISC' based on supply driven character	Supply driven character disappointing	Limited judged from perspective health care insurer	System around dementia patients. Real value can only be assessed if you know what happens after a referral (is need fulfilled?)	Service desk from providers, care offices local governments ('Zorgloket'), health care offices	Supply driven character disappointing	Not applicable
4	Yes, but dementia is a narrow target group	Internet is more often used as source for information	Help with clarification of demand and finding of services, less overburdened informal carers	Young informal carers, professionals	Social Chart GGD, care-offices ('Zorgloketten')	Technique	Yes
5	Yes, also applicable in combination with professional help	Theory of needs of patients that will lead to independence of professional help.	'Empowerment' of patients and information on service offering is valuable	Patients (and informal carers) and professionals!	Nothing comparable to technique and aims	Not applicable	Yes
6	For informal carers	Finding of services	Speed of internet, information retrievable on short term, home health care manageable over longer periods of time	Informal carers and patients in early stages of disease	No	Not applicable	Yes
7	When the right information is available	We receive a lot of requests for this type of information	Finding of information on a earlier time within the process	Informal carers, especially children of patients	Social chart MEE, www.kiesbeter.nl provincial sites RCPP	Clarification of needs	Yes
8	Yes, absolutely	My clients mention the need for less fragmentation and frequently	Conveniently arranged, people do not know where information is, and professionals are unable to refer adequately	Informal carers and patients	No	Not applicable	Yes
9	Yes, absolutely	Interaction with informal carers	Information is made accessible	Informal carers, patients in early stages and professionals	No	Not applicable	Yes
10	Yes	Lack of available, accessible well organized information. Searching time consuming.	User friendliness and distinguishing	Informal carers, professionals, clerks and patients in early stages with Internet knowledge	Social chart MEE, local care offices ('Zorgloketten')	Not comparable, praises 'DEM- DISC'	Yes

Table 9: Opinion of participants of interviews with respect to 'DEM- DISC'

Nr.	Type	Providers model	Commercial model	Community model	Insurer model	Governmental model
1	Full chain	Not so likely based on competition	Provider will not pay a fee for referral, information interesting, but the gathering is complex	Most logical	Doubts objectivity, does not appeal	Most likely
2	National government	Will result in strategic alliance, providers unaware of advantages cooperation	Commercial interests are not compatible with client interests	No experience	Internal conflict of interest, based on financing structure	Does not converge with policies, government distances oneself from central arranging
3	Insurer	Seems possible	possibility	possibility	With cooperation government and patient organization	With cooperation patient organization
4	Informal care (n=2)	Most preferred	Risk of biased information, fees not likely to be paid due differences in scale	Well imaginable	Future possibility	Most preferred based on equality with regard to differences in scale
5	Home care	Not likely as a consequence of competition	Likely	Strong option	Future possibility	Strong possibility if option is as well desired by government itself
6	Nursing home and day care (n=2)	Not likely, funds are withdrawn from direct care budgets	Fear of biased information, no interest in gathered information since patients find themselves in last stage of life	Most likely	Not possible based on financing structure	Most preferred, most 'safe' for providers
7	Patient organization	Would be possible, matches trend, expects financing problems in long term perspective and loss of interest from providers	Not likely, only an option when a construction of preferred relations is created. In case each party buys the same information it is worthless. Hazard of biased information	Most preferred	Difficult based on financing structure and regional embeddings	Most likely
8	Welfare	Possibility.	With participation of patient organization a likely option, most preferred	Interesting, as long as these parties contribute financially	No option, based on financing structure	On national scale an option
9	Informal care and LDP	Not likely	Theoretical option	Most preferred	Future possibility	Locally no option based on geographic spread
10	Local government welfare elderly	Not likely	Financially interesting, hazard biased information	Most preferred	No option as a consequence of financing structure	Likely on either regional or national scale

Table 10: Comments of participants to the interviews on the organizational arrangements



	Type	Added value	Source of revenue	Indirect revenue	Specific contribution	Opinion of 'DEM-DISC'
1	Full chain	Insight in offerings, Information on numbers of patients, carers, user preferences and Internet use	New clients;	Insight in organization and offering for development of new products ;	As asset would be to include information with regard to prevention of dementia, living environments, private care and domotica	Interesting for carers, not likely providers are willing to participate. Outcomes revenue sharing yearly evaluated.
2	National government	Cooperation between providers will eventually results in improvement position of clients. Promotion of cohesion between providers		Information insight in service offerings	Even when not all providers participate the system is able to create a surplus value	Necessary
3	Insurer		Reduction in expenditure as a result of chain orientation	Improvement patient and carers well being, reduction in expenditure, realization of a win- win situation	Participation patient organization required	Not consumer driven enough, value proposition should be created by taking care demand as staring point, not the existing supply
4	Informal care (n=2)	Users will be enabled to find services earlier	More clients in better psychological condition	Being well known in a wider context and earlier in the process.		Enthusiastic, financial contribution should consider differences in scale
5	Home care	Information. Empowerment users, applicable to enlarge knowledge and capabilities of nurses, systematic clarification of demand		Matches mission and vision. Application could prove effectivity new approach and underscore strategy	Application suitable for use by nurses by means of Personal Digital Assistants. Participation of independent party required to intervne in tension caused by competition.	Innovation
6	Nursing home and daycare (n=2)	Beneficial for client	Patient finds adequate solution for care demand		No roles can be missed	Care dedicated to patients final stages of life, no problems due to inadequate referrals.
7	Patient organization	Have tried develop a similar site themselves, which proved impossible based on 'management'. This system would match aims and objectives.	Services are found easier by potential users.	Adequate information	Domain expert, because quality of data determines viability. Patient's interest consists of 'soft' data. Regulation forbids participation with certain commercial parties, like pharmaceutical firms.	Enthusiastic, aware of complex process as consequence of private attempts to deliver a comparable service.
8	Welfare	Being well known and full overview.	Full overview, tool to improve service offering based on full overview services and beat competition. Useful for employees. New clients.	A pleasure to contribute, humanity. Applicable to improve development of new products and increase changes in merging procedures.	'Soft data', general information can be found relatively simple, adjust to user demands.	Enthusiastic, improvement in adequate referrals and finding relevant services by users themselves.
9	Informal care+ LDP	Full overview available services, information.	Tool for employees, both professionals and volunteers.	An answer to a regional need.		Innovation, desires implementation
10	Local government	Applicable for clerks		Enlarged accessibility care and welfare	Independent party for conflicting interests providers.	Desirable service, market adoption complex

Table 11: 'DEM-DISC's' value proposition based on participants of the interviews' participation in the value network

## 6. 1 Expert interviews

Expert interviews are conducted to assess if the interview outcomes form a representative example of the field of 'care'.

The first expert interview was conducted with a not previously interviewed health care insurer 'cure' and revealed that current legislation within either 'cure' or 'care' and 'welfare' does not include obvious business opportunities for 'DEM-DISC'. For that reason the 'insurer model' was discarded correctly. Business opportunities were also unlikely according to this interviewed party, because 'care' and 'welfare' are not in the interest of a health care insurer. Conclusions based on the market analyses were correct.

The second interview was conducted with a manager of a health care office who concentrated on clients and quality. The central theme was which opportunities care providers possess to influence purchasing by the health care offices. Tender procedures are based on both quality and price. Production is limited to the amount purchased by the health care office. Over production by providers will not be compensated. Providers have no chances other than price and quality to distinguish themselves from competitors. The competition experienced by providers which results in fear to cooperate was recognized after some discussion. Subsequently the interest of offering the service by healthcare offices was evoked. In the previous conversations this interest was absent, although reduction of costs generated by improving of efficiency are profits for the health care office. These profits can be preserved by the health care office. Based on the market analyses and the stakeholders analysis this was considered an incentive which could create the health care offices' interest. The previous absence of interest was clarified by the functions and orientation of interviewed persons.

The third expert interview was conducted with a manager of an organization which develops ICT applications in the Twente region. They also experienced problems as a consequence of fear to cooperate. In one of their projects savings in expenditure could be created by cooperation. In that project one employee is able to respond to alarms from all local home care clients and contact the provider concerned. The providers' fear is that their clients will be contacted by competitors. Based on this fear the project failed. They hope to resolve this problem by development of a shared service center, which collects information from providers and distributes it for the providers. Each provider has about 8 to 12 organizations to which data should be made available. An administrative burden will be taken over by this center. The idea is that the shared service center will provide so many benefits that it will evoke cooperation and diminish fear of competition.

## Construction of Hierarchy for Analytic Hierarchy Process

<b>With regard to economic aspects</b>	<b>With regard to roles</b>	<b>With regard to data</b>	<b>With regard to aims and objectives</b>
Economic equality with regard to differences in scale (4, 8). Investments related to financial strength (1, 4) Beneficial returns (4). Expertise employees (4, 5, 8, 9, 10) Information on user preferences and overview available service offerings (1, 2, 7, 8, 9, 10)	Equal chances new clients (1, 4), Independent party involved (1, 3, 5, 8, 10). Protection of patients (3, 8, 9, 10). Patient party involved (3, 8).	Protection of patients (1, 3, 8, 9, 10). Influence on how your services are represented (based on completeness) (7) Reliability and accuracy (1, 2, 3, 4, 5, 7, 8, 9, 10). Up to date (1, 2, 4, 5, 7, 8, 9, 10). No biased information. Objectivity (1, 2, 7, 8, 9).	Compatible interests (1, 2, 4, 7, 8, 9, 10) Patient organization involved (3, 8)
<b>Acceptable profits</b>	<b>Acceptable division of roles</b>	<b>Quality of data</b>	<b>Clear defined network strategy</b>
In a viable business model a service needs to generate sufficient profits. For a stable business model it is important costs, risks, profits and investments are divided in a way that satisfies all parties. An imbalance creates friction between parties, which manifests itself in poor services. Are financial costs and benefits in balance with responsibilities?	In a value network it is important to keep the number of participating parties as small as possible. The burden of coordination rises with complexity if the value network. Parties with an indispensable role with respect to the value proposition possess the most power. Each partner has an own vision with respect to desired roles, deployment of means and required qualities to conduct tasks. Satisfaction will be based on extent to which means and skills complement to each other.	Data should be complete, accurate and up-to date. The quality of data is a condition to offer the service-concept to users.	For effective cooperation it is necessary that parties tune interests and strategic aims to a certain level by developing a joint network strategy. The network strategy describes how cooperating parties jointly expect to create value for a specific group and how it contributes to interests and strategic aims of the different parties.

Table 12: Comments of participants on which the criteria of the AHP Hierarchy are constructed

Participants of the interviews commented on the organizational arrangements. These comments were clustered in the areas: ‘economic aspects’, ‘roles’, ‘data’ and ‘aims and objectives’. The table shows the comments, who discussed the comment and how the comments are summarized in the FBBM success- and design factors.

## 6.2 Outcomes AHP

Goal of the AHP is: What is the best business model for 'DEM-DISC'?

The hierarchy is constructed from the criteria 'Quality of data', 'Clear defined network strategy', 'Acceptable profit-sharing' and 'Acceptable division of roles'. The participants (n=2) agreed with the constructed hierarchy (no criteria had to be deleted or entered). The first pair wise comparisons were made to assign relative weights to the criteria.

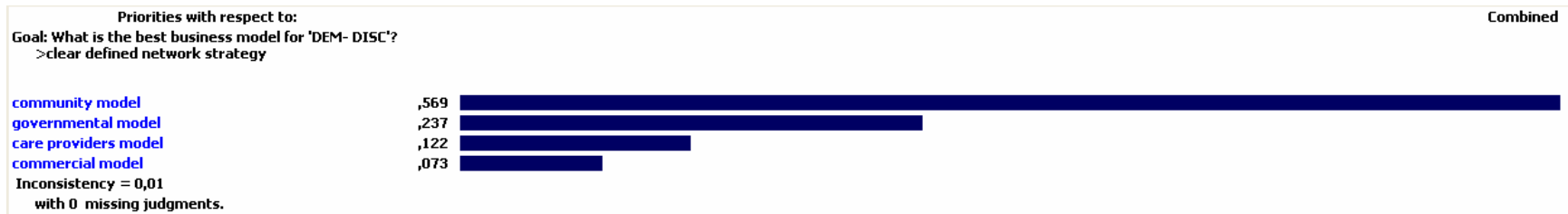
- Quality of data: 0.646
- Clear defined network strategy: 0.195
- Acceptable profit-sharing: 0.102
- Acceptable division of roles: 0.058



Based on each criterion the scores per alternative will be presented.



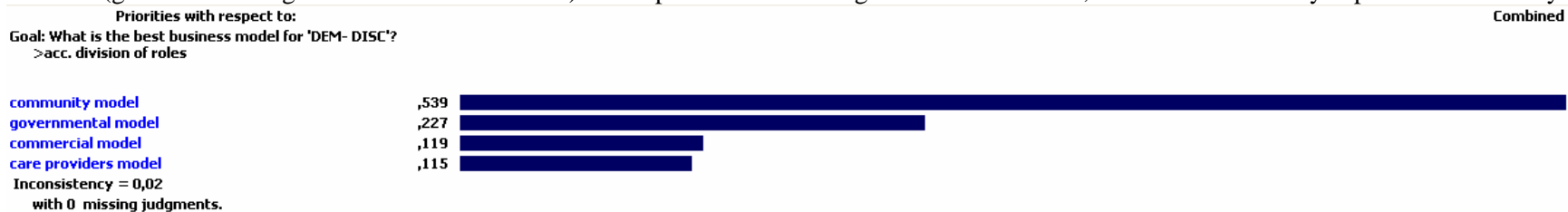
With respect to 'Quality of data' the 'community model' was best preferred. Participants based their opinion on the expectation that organization stemming from an interest group would result in the best quality of data based on their focus on users and providers would be most willing to participate in this model by delivering adequate data. The organization would feel secure and fear of competition would be less threatening. The 'governmental model' was preferred least since the participants considered it more to be in the interest of the government to obtain a particular site, than maintaining adequate data.



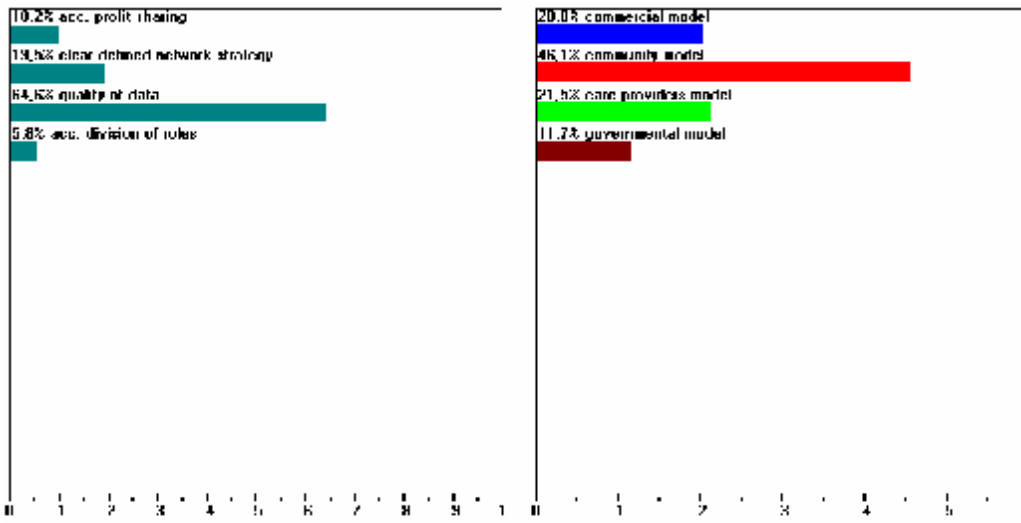
Based on the participants opinion the 'Clear defined network strategy' would be best represented in the 'community model'. The 'governmental model' would be their second choice. The 'commercial model' was least preferred in this perspective. The expectancy among participants is the commercial interests will not be compatible with interests of patients and informal carers on a long term basis. This argument was no problem with respect to the 'community model' which explains the differences in scores. Network value and customer value are most compatible resulting in a clear defined network strategy.



With respect to 'Acceptable profit sharing' the 'commercial model' was preferred best. The cost benefit sharing was not questioned. Participants valued the aspect that this model could offer a service and survive independently of funds or subsidy. One of the participants was not afraid for inadequate data based on the commercial interests and assigned a 2 favoring the 'commercial model'. The second participant believed his arguments but preferred the 'community model' by assigning a 7 in this respect. This pair wise comparison contained the widest geometric variance (geometric average 1.87 and variance 0.601). Least preferred was the 'governmental model', which would be fully dependent on subsidy.



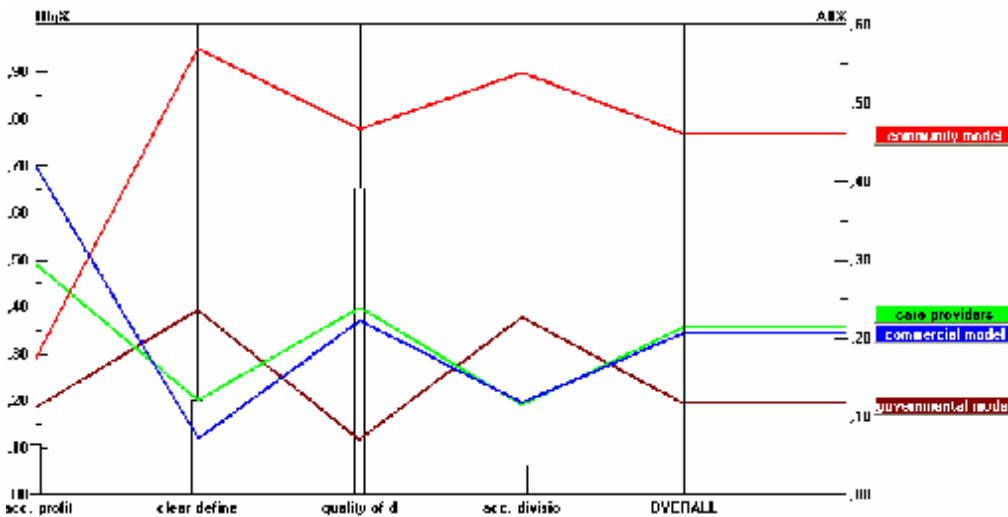
With respect to 'Acceptable division of roles' the community model scored best. The argument was the focus on patients' well being. The 'providers' model' was preferred least. The providers' motives for participation, especially in long term perspective were questioned. Disappointing results might end willingness to participate.



Sensitivity analysis: Goal: What is the best business model for DPHM DISTRICT? Distributive Mode

Table 19: The relative weights of criteria and overall preferences for the alternatives.

The left part of the table shows the relative weight assigned to the criteria. The right part shows the preferences for the alternatives in percentages. The ‘commercial model’ and the ‘care providers’ model’ have comparable outcomes. Based on the discussion between the participants an explanation is that both strive for a financial benefit.



Sensitivity analysis: Goal: What is the best business model for DPHM DISTRICT? Distributive Mode

Table 20: Performance of the alternatives per criteria

The bars in the table represent the criteria and their height visualizes the assigned relative weights. The colored lines represent the four models. It is visible that with regard to ‘acceptable profit sharing’ the ‘commercial model’ and the ‘care providers’ model’ are the most preferred alternatives, based on revenue sharing options. For the remaining criteria the ‘community model’ is most preferred, which is emphasized in the overall outcome.

## **Chapter 7: Conclusions and discussion**

Section 7.1 will describe the conclusions stemming from the conducted study. Subsequently section 7.2 will present the discussion with regard to the study. Finally section 7.3 will present the limitations of the study.

### **7.1 Conclusions**

Based on the market analysis in the study for a viable business model for 'DEM-DISC' no obvious chance for a viable business model in the field of 'care' was found. Financial profits which could be generated are directed away from the investing parties. In the chain 'cure', chain cooperation can result in reduction of expenditure. For example in case of diabetes patients, investment in information can prevent diabetic foot or coma. Investments of involved parties are evoked and rewarded by financial benefits. The cooperation is beneficial for parties involved. In the chain 'care' this incentive lacks. Even when care providers (providers of care distributed via the Exceptional Medical Expenses Act) participate in any type of project the only revenue can be more clients up to the maximum level contracted by the health care office and brand awareness. Since the market of 'care' is characterized by scarcity it is not a problem to attract clients.

Legislation provides no incentives to providers to cooperate and create business collaboration between care and welfare in a region. Nobody feels responsible for fragmentation issues. The National Dementia Program (NDP) is an experiment recently introduced by the government. The NDP functions as an instrument to offer regions their own process and create improvements by evoking responsibility.

Based on the role of the health care office there is little to no space for providers to extend their market share. Extra mural care providers are forced to compete with competitors on both price and quality in tender procedures. These procedures tend to stimulate efficiency. Intra mural care providers are faced with challenges due to changes in compensation. One witnesses an increase in mergers as a response to market reforms. As a consequence of mergers there are on average three or four major players on a local market. Full chain providers are somewhat questionable with respect to willingness to participate based on the aspect that services of multiple providers are included in the system. Providers are anxious about cooperation and competition. Some providers mention that cooperation will only be possible when cooperation is conducted via existing forms of cooperation. In case a large number of providers cooperate the anxiety decreases, and providers are more afraid to not be excluded from the system. Resistance could be dispelled by creating a cooperation of considerable size to persuade other providers. As a consequence it is possible to start with a number of willing organizations as a result of which others are persuaded to participate.

None of the participants to the interviews questions the need and the value of the service for users. The providers who play a role at end stages of the disease are convinced that patients, their relatives and professionals can find their (palliative) services. They still value 'DEM-DISC's' concept because the patients' home situation remains manageable for informal carers for extended periods of time.

The information which possibly could be generated by the system is considered valuable by providers. Providers' value is generated by the full overview of available services which is applicable for adequate referrals, information for development of new products and in preparation for tender procedures and brand awareness. All providers of services who participated in the

interviews would like their services to be included. In case costs are involved for participation economic aspects will be criticized each year to judge the next year's participation.

Participation in 'DEM- DISC' will not result in financial benefits comparable to those generated by the chain 'cure'. No 'win- win' situation can be created. 'DEM-DISC's' network value seems to be the largest for stakeholders who play a role early in the process of dementia. A recommendation is to assess in which way more network value for providers could be generated in order to evoke willingness to participate by decreasing resilience for cooperation and fear of competition. Although every interviewed party would like their services included, the fear of competition was mentioned frequently. An increased network value would reduce fear of cooperation and evoke required cooperation. Resilience might be decreased by increased network value. Inclusion of all providers and their services creates the largest customer value.

Value creation is an important element in health care. Health care deals with multiple interests by which it distinguishes itself from ordinary markets. Users of health care are unsure when and if services are consumed, information asymmetry characterizes the market, costs and scarcity influence availability, etc. Value creation can be assessed via business models, although not all the created value will be included. Value is not always fully measurable in economic outputs. Chesbrough and Rosenbloom measure value by economic outputs generated by a technology. The FBBM measures viability of the business model based on the sum of network value and customer value. The perspective of value creation enables the adoption of the wide approach which is required to comply with the multiple interests in health care, and establish the value created by an innovation.

Five possible organizational arrangements were found. Four of them complied with the requirement for viability. Participants of the interviews commented on the models, based on these comments criteria were constructed. The criteria which stem from the FBBM can be applied to assess or build business models. Constructed criteria are:

- Acceptable profits
- Clear defined network strategy
- Quality of data
- Acceptable division of roles.

The assessment was conducted by an Analytic Hierarchy Process (AHP). The AHP proved a valuable extension to the Freeband Business Blueprint Method (FBBM). The FBBM stems from the STOF model and includes critical success factors and critical design factors. The AHP provides an elaboration in this perspective, based on participants enthusiasm with regard to the method and the options provided by the technique. Compromise or consensus within a network can be created by the process the AHP offers to its participants. The AHP was applied to select the best business model for 'DEM-DISC'. The criteria formed the hierarchy. Participants assigned relative weights. The four remaining models formed the alternatives, from which the best model for 'DEM-DISC' would be chosen based on pair wise comparisons. All organizational arrangements which form preliminary bases for a business model concentrate around the concept of different parties offering the service. The role of provider could be executed by governments, providers, commercial parties and interest groups. These parties are present in the four models which formed the alternatives in the AHP:

- Providers model
- Governmental model
- Community model
- Commercial model.



The model which was selected as best was the 'community model'. In this model an interest group organizes the service. Revenue sharing is based on aims and objectives that are met by offering the service. They create an added value for which a financial contribution will be acceptable. Critique on this model could be no financial benefits besides ads and sponsorship are created. Disadvantage is that users appreciate absence of commercial sponsorship and advertisement. Interest groups comply with strict conditions based on which sponsors or advertisement is accepted. A condition is that no conflict of interest emerges, so only non-sector related ads are allowed. Users will easily separate serious information from advertisement. Confusion will be prevented. Advantage is that the model creates trust for in the network required parties. Several participants to the interviews mentioned participation of an interest group would be required to monitor users' interests.

This model seems to distinguish itself by creating the best match between customer value and network value. In both the interviews and the AHP the model was most preferred or considered most likely. Willingness to participate is evoked by participation of a consumer party. No conflict of interest can be found with respect to the value proposition for users. Participants to the AHP valued the model best with regard to 'quality of data', 'clear network strategy' and 'acceptable division of rules'. Part of their trust is created by the expectancy interests are compatible in a long term perspective. The 'governmental model' would in their mind be the least capable of maintaining adequate data. Based on commercial interests both the 'commercial model' and the 'care providers' model' would obey the condition of adequate data as well. Fear was that the commercial interest in these models would prevent users' trust. With respect to the criteria 'acceptable profits' the 'commercial model' scored significantly higher than all others. In the interview questions were placed with respect to this model, only once the model was most preferred.

The 'community model' is found in the United Kingdom where the Alzheimers's association provides an overview of available services and their addresses per region. This site has no interactive elements, besides selecting your region of residence. The service is paid for by Alzheimer's society. No commercial activities are conducted to generate extra income.

The model is also found in the United States and called Alzheimer's association CareFinder. Alzheimer's offers the service, partly funded by a grant from the Administration on Ageing, United States Department of Health and Human Services. This model implicates a combined model of the developed organizational arrangements ('community model' and 'governmental model'). Advantages are the instant recognition of the organization behind the site for establishing credibility and absence of commercial sponsorship. 'Alzheimer's' association CareFinder' can be found on the United States' Alzheimer's' homepage where it has a place between multiple sponsored links ('commercial model').

For a viable business model for 'DEM-DISC' the option of a combination of models should not be excluded.

## 7.2 Discussion

Based on practice a combination of models is not considered impossible. The ‘commercial model’ seems held up by hostility, based on the interviews. The word ‘commercial’ is for a lot of people not a likely option in the health care context. It is not considered preferable for the users. Hence there are quite a number of examples organized via commercial sponsorship that people are unaware of; blood checks in supermarkets offered by the heart foundation (in Dutch: Hartstichting) are sponsored by a producer of diet butter products, on line guidance to loose weight is fully sponsored by a pharmaceutical firm, and so on.

A subject that was discussed in the interviews was ‘DEM-DISC’s’ most preferable scale. The aim is national coverage, in which a user can select his or her region. Region is not a well defined concept. Since most of the care relevant to dementia patients and informal carers is reimbursed via the AWBZ it seems preferable to consider the 32 regions of the health care offices in this perspective. Each health care office is free to purchase care in the way they prefer since the duty to contract has been resolved. Between regions one finds some differences in methods of purchasing and purchased care can differ as well. Regional embeddings based on for example Dutch provinces would complicate your data, since the reimbursed services are not available for every inhabitant of that region. By following the health care offices regions these problems can be prevented.

A few participants of the interviews asked why the user does not have to pay a fee for usage of the system. This view is not adopted by the researchers and from their perspective does not seem preferable. The option is not excluded, but based on preferences that were never subject of study.

Stemming from this study two tracks will be followed by enthusiast participants to the interviews. At first the NDP Twente will consult the Province with respect to funding, since the ‘DEM-DISC’s’ aims are compatible with the Provinces’ aims. Secondly it might be an option if all health care offices are interested in ‘DEM-DISC’, the health care offices become ‘DEM-DISC’s’ provider.

Market reforms, will within in a limited timeframe, end in integration of the AWBZ in the mandatory health care insurance. This creates new opportunities and threats. It implicates results are up to date at this point of time. Fragmentation issues will remain or even enlarge. It is not likely insurers will reimburse taxi expenses, informal care or domestic care. These expenses remain for local governments. Furthermore the insurer will only offer contracted care to its insured persons. Availability of care will be linked to the insurer and policy of the patients, which might stimulate fragmentation. The patients’ well-known providers might not be contracted by its insurer, with the result that a search for information becomes even more complex.

## 7.3 Limitations

The interviewed parties do not include the academic medical profession who work in the field of health care for dementia. Adapting the value proposition to their needs would evoke the health care insurers’ interest.

The AHP was conducted with 2 participants. Because the AHP meeting was scheduled in the summer period, required time and travel distances no more interviewees were able to attend.

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## Appendix A

Table most expensive diseases based on costs per case per disease in 1999

Diagnosegroep	Totale kosten (mln. euro)	Aandeel in totale uitgaven (%)	Aandeel AWBZ (%)	Aandeel 2 <sup>e</sup> compartiment (%)	Kosten per ziektegeval (euro)
Dementie	1.760	4,9	98	2	30.614
Verstandelijke handicap	2.780	7,7	100	0	27.245
Slokdarmkanker	23	0,1	4	96	22.411
Chronische huidzweren, inclusief decubitus en open been	79	0,2	17	83	19.404
Schizofrenie	380	1,1	85	15	13.962
Hersenvliesontsteking	27	0,1	58	42	13.047
Beroerte	1.029	2,9	60	40	7.946
HIV/AIDS	15	0	20	79	7.211
Vroeggeboorten	104	0,3	0	100	7.014
Multiple sclerose	78	0,2	54	46	5.805
Inflammatoire darmziekten	64	0,2	0	100	5.790
Longkanker	104	0,3	0	100	5.244
Sepsis	43	0,1	59	41	4.404
Ziekte van Parkinson	137	0,4	69	31	4.208
Zwangerschap, bevalling en kraambed	796	2,2	1	99	4.028
Maagkanker	33	0,1	9	91	3.743
Non-Hodgkin lymfomen	39	0,1	7	93	3.495
Zweren van maag en twaalf vingerige darm	62	0,2	17	83	3.223
Angststoornissen	180	0,5	34	64	2.729
Dikke darm- en endeldarmkanker	124	0,3	9	91	2.194
Subtotaal	7.857	21,8	73	27	
Totaal gezondheidszorg	36.033		39	52	

Derived from De Jong et al. (2005):



## Appendix B

### B 1: Problem areas NDP in Dutch.

### B 2: Problem areas Camberwell Assessment of Needs for Elderly



#### 1. Niet plus gevoel

In het begin van het ziekteproces is er vaak een gevoel van onbehagen en onduidelijkheid bij de patiënt, de familie of bij bijvoorbeeld buren. Men vermoedt misschien dementie of twijfelt eraan maar dat gevoel is vaag. Betrokkene gedraagt zich anders, voelt zich depressief of doet bijvoorbeeld juist overdreven opgewekt.

#### 2. Wat is er aan de hand en wat kan helpen?

Na het stellen van de diagnose dementie vallen puzzelstukken op hun plaats. Maar patiënten en familie weten lang niet altijd hoe ze de dagelijkse problemen kunnen oplossen. Bovendien is de diagnose vaak zeer ingrijpend en kan gepaard gaan met een depressief gevoel van niks meer waard zijn. Niet alleen rondom de diagnose maar tijdens het hele ziekteproces stellen cliënten en mantelzorgers de vraag: wat is er aan de hand en wat kan helpen? Bij wie kan ik terecht met vragen en voor hulp?

#### 3. Bang, boos en in de war

Mensen met dementie kunnen allerlei gedrags- en stemmingsproblemen hebben. Dit kan door de dementie ontstaan of bijvoorbeeld door de manier waarop de omgeving van de cliënt omgaat met de ziekte. Voorbeelden zijn tegendraads zijn, boosheid, achterdocht, lusteloosheid of ontremming. Of het gedrag een probleem is, wisselt en hangt sterk af van de draagkracht van de mantelzorger. Om een juiste oplossing te vinden is inzicht in de oorzaken van de gedrags- en stemmingsproblemen nodig.

#### 4. Er alleen voor staan

Er alleen voor staan is een probleem van zowel de cliënt als de mantelzorger. Het gaat in dit probleemveld om praktische handelingen zoals autorijden, financiën, schoonmaken, de tuin onderhouden. De cliënt kan het niet meer en iemand moet het overnemen. Er alleen voor staan is bij de toename van dementie een probleem.

#### 5. Contacten mijden

De cliënt richt zich steeds meer op de wereld dicht om zich heen. De omgeving begrijpt dit niet en de aansluiting met anderen wordt lastig. De cliënt gaat nergens meer heen, er komt niemand meer op bezoek. De cliënt herkent steeds minder mensen. De partner is aan huis gebonden en dit veroorzaakt een sociaal isolement. Uitwonende kinderen hebben een eigen kijk op de situatie aankijken en dit kan tot spanningen leiden tussen de partner en kinderen.

#### 6. Lichamelijke zorg

Problemen bij de lichaamsverzorging zoals het aan- en uitkleden, wassen, zelf eten en omgaan met incontinentie. Als de thuiszorg niet aanwezig is, komt de hulp op de schouders van de mantelzorger terecht. Dat kan een fysieke en psychische belasting geven. Wanneer de patiënt het probleem niet onderkent, dreigt overbelasting voor de mantelzorger. De woning is niet altijd geschikt om de zorg te leveren: afgelegen, te veel trappen, te weinig ruimte op de begane grond.

## **7. Gevaar**

Cliënten zijn vergeetachtig en weten niet meer hoe ze bepaalde handelingen moeten uitvoeren. Dan is thuisblijven zonder toezicht gevaarlijk (vuur, gas, kortsluiting). Daarnaast zijn cliënten die alleen thuis zijn weerloos. Ze zijn doorgaans minder goed ter been en de kans op vallen en ongelukken in huis is groter, zeker bij rusteloze patiënten. De omgeving maakt zich zorgen over bijvoorbeeld de vervuiling van het huis, verwaarlozing of vermissing van de patiënt of onveilige situaties met vuur of gas.

## **8. Ook nog gezondheidsproblemen**

Naast de dementie kunnen er chronische of acute gezondheidsproblemen zijn die moeilijk te behandelen zijn. De cliënt heeft door de dementie weinig inzicht in zijn ziekte, vergeet pillen te slikken of behandeladviezen op te volgen. Anderzijds kan de cliënt extra onrustig of verward zijn door bijvoorbeeld een blaasontsteking of pijn aan tanden en kiezen zonder dat de cliënt het lichamelijke probleem kan duiden.

## **9. Verlies**

Door lichamelijke en verstandelijke achteruitgang gaat de grip op het eigen verloren. De patiënt wordt steeds afhankelijker van zijn zorgverleners. Mantelzorgers van cliënten raken hun oorspronkelijke partner kwijt, door het ziektebeeld lijkt het een ander persoon geworden. De verwachtingen en het toekomstbeeld op de relatie en het eigen leven veranderen radicaal. Het loslaten is een rouwproces dat met veel emoties gepaard gaat.

## **10. Het wordt me te veel**

Het verdriet om de ziekte van de cliënt in combinatie met het regelen van de zorg is zwaar. De mantelzorger moet 24 uur per dag klaar staan. Dat kan ten koste gaan van de aandacht die de mantelzorger voor zichzelf heeft. Door de problemen kan uitputting optreden.

## **11. Zeggenschap inleveren en kwijtraken**

Mantelzorgers en cliënten voelen zich betutteld door zorgverleners. Ze vinden dat hun privacy en zeggenschap wordt afgenomen en accepteren dat niet of vinden dat ze niet genoeg betrokken worden bij de zorg. Mantelzorgers of cliënten vinden het lastig om dit probleem te bespreken met de hulpverleners omdat ze afhankelijk zijn van de hulp.

## **12. In goede en slechte tijden**

Mantelzorgers en andere naasten voelen de zorg als een verplichting aan hun demente partner of ouder, omdat de ander hetzelfde ook voor hen gedaan zou hebben of al gedaan heeft. Soms is het vooral de omgeving die deze zorg van hen verwacht. Het is een moreel dilemma als blijkt dat het niet eenvoudig – of onmogelijk – is om deze plicht te vervullen. Men voelt zich schuldig over het overdragen van zorg of bij opname in een instelling.

## **13. Miscommunicatie met hulpverleners**

Patiënt en naasten voelen dat hulpverleners zich niet echt verdiepen in hun beleving en problemen of er zijn de misverstanden in de communicatie die met taal en/of met cultuur te maken hebben. Ook hebben cliënten en mantelzorgers er last van dat hulpverleners onvoldoende doorverwijzen of samenwerken bij het oplossen van hun problemen.

## **14. Weerstand tegen opname**

Een heel grote angst van cliënten zelf en van mantelzorgers is een mogelijke opname in het verzorgings- of verpleeghuis. Die weerstand kan blijven bestaan na de opname in een verzorgingshuis of verpleeghuis (Meerveld et al 2005).

## B 2: Camberwell Assessment of Needs for Elderly

Appendix. Measure of unmet need		
Item	Yes	No
<b>Do you need more help with/help providing:</b>		
<i>Activities of Daily Living help</i>		
1. Helping your loved one bathe		
2. Helping your loved one dress	---	---
3. Helping your loved one use the toilet	---	---
4. Helping your loved one walk around		
5. Helping your loved one get in/out of bed		
<i>Instrumental Activities of Daily Living help</i>		
1. Helping your loved one take medications	---	---
2. Cooking or preparing meals	---	---
3. Housekeeping/cleaning	---	---
4. Doing laundry	---	---
5. Driving your loved one around	---	---
6. Managing finances	---	---
<i>Dementia symptoms</i>		
1. Managing or dealing with your loved one's behavior (e.g., wandering, acting different, crying or screaming)	---	---
2. Dealing with your loved one's memory loss	---	---
<i>Hours of care</i>		
1. Providing care and assistance at night	---	---
2. Providing care and assistance during the day	---	---
3. Providing care and assistance during the weekend	---	---
<i>Formal support</i>		
1. Case management services (e.g., someone to help you find the right services) for your loved one	---	---
2. Homemaker services to help you around the house	---	---
3. Home delivered meals for either your loved one or you		
4. A support group to share experiences with others in the same situation	---	---
5. Training to help you deal with the mood or behavior problems of your loved one	---	---
6. Counseling to manage stress, depression, or alcohol abuse	---	---
7. Financial advice		
8. Legal advice		
<i>Information</i>		
1. Medicare/Medicaid eligibility	---	---
2. Asset protection		
3. Choosing the right nursing home or hospital		
4. Your loved one's illness		
<i>Confidante</i>		
1. Counseling from the local pastor/priest	---	---
2. Support from the local church	---	---
3. Visits from family or friends		
4. Family support for the care you provide		
5. Feelings of closeness and connectedness with those around you	---	---
6. Intimacy from your loved one	---	---

Derived from: Gaugler, J. E., Anderson K. A., Leach, C. R., Smith, C. D. , Schmitt, F. A., Mendiondo, M. *American Journal of Alzheimer's Disease and Other Dementias* Volume 19, Number 6, November/December 2004

## Appendix C

### Protocol interviews providers

#### Case selection:

All relevant stakeholders in relation to DEM- disc will be approached to participate in interviews. Since DEM- discs core business is the field of health care and welfare regarding dementia for both patients and their (in-) formal carers that is the area where stakeholders will be identified. Selected stakeholders are providers of health care and welfare, as well as stakeholders identified based on a study of health care and informal care governance and legislation. The relevant stakeholders will be approached to participate in interviews.

#### Code of conduct:

Interviewees will receive an information kit. This kit will contain information regarding DEM- discs and the services it aims to provide. This kit will be sent to them in advance of the interview. A framework to conduct interviews will be developed. The general topic is to discuss options for financial and organization structures that eventually may result in a viable business model for DEM- disc. Value webs will be used to visualize roles and stakes in DEM- discs complex organizational arrangement.

#### Case study framework:

A first round of interviews will lead to an extended literature study, after which interviewees possible will be approached once more. The aspiration is to invite interested and relevant stakeholders for a Freeband Business Blueprint meeting and perform a quick scan and detailing of the organizational and financial domain.

#### Research framework:

- What value is offered to end- users in a specific context (value proposition)?
- The actors, roles and relationships needed to realize the service (value network).
- How revenues are generated and divided among actors (revenue model).
- The fundamental organization of information that is necessary to deliver a service offering (legislation and services offered by providers of health care and welfare).

In essence there are four clusters of related topics. They are identified based on the STOF- model of Haaker et al. (2004) and consist of the service domain, the technology domain, the organizational domain and the financial domain. The end result of the interviews has to be the ability to predict network value and customer value. Doing so, the viability of the (different) business models can be assessed. The guidelines for success full cooperation in development and exploitation of innovative ICT services will be an excellent tool to guide participants (Haaker, Oerlemans, Steen and De Vos, 2004).

#### Interview protocol:

a) Check if information kit was received properly. If necessary, explain DEM- disc.

1. Do you think there is a need for a service like DEM- disc?
2. On what grounds did you base your opinion?
3. What do you think is the customer value or value proposition?
4. To which customer groups?
5. Do you know complementary services or products?
6. How is the product different from competing products?

7. Would you like your services to be in DEM- discs services, so they can be offered to users?

In order to adequately organize a service like DEM- disc we would like to brainstorm about questions in the field of organizing and financing the service. The consideration to do so is based on the assumption that it is important innovations are offered a 'chance to land'. It is a shame if innovations only remain as unfeasible ideas. Participation from the field of the actual dementia care is a condition to see threats and opportunities.

8. In order to offer a service like DEM- disc in a reliable way, we need adequate data. The engine builds the service bundles based on the inserted data. Data regarding service offerings have to be up to date. Do you think it is possible to timely inform and adapt DEM- disc, in case any changes in the service offering occur?
9. Legislation is a second part that is important in order to guarantee DEM- discs reliability. It is our impression legislation changes quite regularly. Is this assumption right? In what way does your organization keep knowledge regarding legislation up to date?

DEM- discs primary user group will probably be 'informal carers'. A major challenge in developing DEM- disc is revenue sharing. Finding possibilities to organize the financial aspects can result in development of a possible business model, as well as speeding up processes on a strategic level with regard to the innovative services and challenges in revenue sharing being modeled in different business models. The approach to come to these options is to concentrate on different possibilities, free of obligations and in confidentiality. See the discussion as a 'brainstorm' from which results give us ways to calculate if there is a possibility to 'land' for DEM- disc.

10. Here are possible diagrams of value networks (interviewer has different diagrams). Can you imagine this type of organization for a service like DEM- disc? Do you agree this organizational form is at least an option? Where do you see complications? Based on what do you doubt?
11. Why would your organization be interested in participating in DEM- disc (or not)? Why does your firm expect participating in this network to be success full? What do you bring? What do they bring? What is the added value for other firms in the value system? What is the added value for your firm?
12. Which products and services are the most significant source of revenue? Can you describe, in general terms, the way you expect to make money?
13. What are the revenues? Relation revenues number of users? Indirect revenues (customer retention, market share, market extension)? What are non- material benefits (strategic, competitive advantage, competitive response)?
14. (show figure) What is the specific contribution of individual participants in the value web? Can contributions be missed and even then make the service possible? With regard to actors that don't directly deliver customer value to end- users; what is their specific contribution?

Based on your enthusiasm and valuable cooperation we would like to invite you to a FBB meeting. In a FBB meeting different parties meet and discuss on service, technology, organization and financial aspects. This meeting is as well organized in the form of a brainstorm and participants together make a quick scan of the service, DEM- disc in this case. Participation is voluntary, confidential (results will not be published by naming participants) and free of obligations.

Thank you for participating in the interview. A written document with the content of this interview will be sent to you for your approval.

## Appendix D

In the table the critical success factors from the FBB method are printed in bold. The design factors which stem from the success factors are presented under the success factors.

<b>Acceptable division of roles</b>	<b>Acceptable profits</b>	<b>Clear collective network strategy</b>	<b>Clearly defined target group</b>	<b>Clear value proposition</b>	<b>Quality of service delivery</b>
Division of roles	Price fixing for end user	Division of roles	Target group	Context in which service is applied	Distribution of resources and competences
Division of aids and competences	Risks for viability	Risks for viability	Context in which service is applied	Value elements of the service	Complexity of value network
Partner selection	Outsourcing	Partner selection	Value elements of the service	Price fixing for end user	Involvement clients and end-users in design service
Outsourcing	Distribution of investments	Accessibility and openness of value network	Effort user has to conduct	Effort user has to conduct	Safety of information and communication
Orchestration of value network	Distribution of benefits	Accessibility of service for target group	Trust of users in service	Service and processes	Technical quality
	Appreciation of resources and competences	Complexity of value network	Accessibility of service for users	Dealing with different versions	Integration of systems
	Phasing of investments	Co-ompetition		Branding	Scalability of technique
				Personalization	Standardization
				Involvement clients and end-users in design service	Accessibility of service for users
					Technical accessibility for content providers
					Management of user profiles

