Chapter 1

General Introduction

Background

Vision loss can be the result of age-related degenerative processes, congenital conditions, trauma, or disease. Although some causes of vision loss (such as refractive errors and cataract) can be treated, this is not always possible or sufficient to (fully) regain vision. Age is a risk factor for vision loss and, in the Netherlands, over 300,000 elderly are known to have low vision.[1]

In the Netherlands, there are specific rehabilitation services to help persons with (irreversible) visual impairment to maintain or improve quality of life, independent living and participation in society. For the most optimal results, rehabilitation must match the patient's individual needs. However, because the number of visually impaired persons is expected to rise in the coming next decades, more efficiently organized eye care and visual rehabilitation services are required in the near future.

In 1998, the Netherlands Organization for Health Research and Development (ZonMw) started the research program 'InZicht' which finances scientific research applied in low vision rehabilitation practice. The aim is to improve care and, thus, the quality of life of visually impaired persons. In order to achieve more efficient and better rehabilitation for visually impaired persons, the work presented in this thesis was funded by ZonMw InZicht and carried out together with Sensis (now part of Royal Dutch Visio).

Definition of visual impairment

Many definitions are used to describe ´visual impairment´. The World Health Organization (WHO) developed the International Statistical Classification of Diseases, Injuries and Causes of Death (ICD-10)[2] which is often used to classify visual impairment in several categories. Measurement is made in the better eye, with the best possible correction. Blindness is defined as a visual acuity of less than 3/60 or a corresponding visual field loss of less than 10 degrees. Low vision is defined as a visual acuity of less than 6/18, or a corresponding visual field loss of less than 20 degrees, although better than in case of blindness. Visual acuity and visual field are important factors of visual impairment, but other factors such as contrast sensitivity, problems with, for example, low/high light levels, severe problems with reading, and/or diplopia may also contribute to visual disability.

Prevalence and main causes of visual impairment

In 2002, the WHO estimated the worldwide number of people with blindness at 37 million and of persons with low vision at 124 million.[3] In 2010, the WHO estimated these figures to be 39 and 246 million, respectively.[4] About 90% of the world's visually impaired live in developing countries[5] and prevalence rates vary widely between countries.

In developed countries, age and visual impairment are strongly associated.[6] Large population-based studies in the USA show that prevalence rates for visual impairment and blindness are 0.6-2.1% and 0.1-0.9%, respectively.[7] As a result of demographic aging, the number of (irreversible) visual impairments is expected to rise in the coming decades. In a prognostic study by Limburg et al.,[8] the prevalence of low vision and blindness in the Netherlands (according to the WHO criteria) is expected to increase between 2005 and 2020 from 1.01% to 1.19% for visual impairment and from 0.40% to 0.43% for blindness. In 2011, Keunen et al. reported that the number of persons in the Netherlands with a demand for eye-care services is expected to increase by 200-300% between 2010 and 2020, mainly due to new treatment options and aging;[1] moreover, they expect the number of blind and visually impaired persons to increase by 20%. This will lead to increasing pressure on visual rehabilitation services.[1;9] Since budgets in healthcare are certainly not unlimited, this increase in rehabilitation demands effective and efficiently organized visual rehabilitation services in the near future.

Apart from prevalence rates, also causes of visual impairment vary widely between countries due to differences in the health and eye-care systems. Worldwide, the main causes of visual impairment are uncorrected refractive errors (43%) followed by cataract (33%). In industrialized countries, including the Netherlands,[8] the main cause of serious visual loss in adults is age-related macular degeneration (AMD).[6;7;10-12]

AMD is a disorder of the center of the retina: the macular lutea or fovea. The incidence is strongly related to age,[12] but other aspects such as genetics, smoking habits and nutrition are also associated with AMD.[13] There is a 'wet' and a 'dry' form. About 80% of the patients has the 'dry' form as a result of atrophy of the retinal pigment epithelial layer, underneath the retina. About 10% of the patients has the 'wet' form, in which abnormal blood vessel growth leads to blood and protein leakage underneath the macula causing vision loss. The remainder has both forms. Degeneration of the fovea gradually decreases central vision, as well as the ability to see details and colors. The peripheral vision remains, generally allowing activities such as walking on the street. However, the central vision loss causes problems such as reading or recognizing faces. Currently, there is no treatment available for the dry form of AMD, leaving low vision rehabilitation as a last resort.

Cataract is the eye disease with the highest prevalence in the Netherlands[1] and is the second frequent cause of visual impairment in the

Netherlands.[8;12] Cataract causes a gradual loss of vision, often taking months to years, which frequently leads to discovery in an advanced stage. Age is an important risk factor, as are hereditary factors, environmental factors (e.g., exposure to sunlight), medical conditions (e.g., diabetes) and/or lifestyle habits (e.g., smoking and alcohol use).[14] Cataract induces a loss of transparency of the lens, which blocks or diffuses light. This causes symptoms such as glare, haloes, and blurred vision, without a specific central or peripheral visual field loss. Cataract can generally be successfully treated by extracapsular cataract extraction and implantation of an intraocular lens; however, this may not be possible, e.g., in case of additional eye conditions.

Due to the increasing numbers of patients with obesity in many developed countries (including the Netherlands), the number of patients with diabetes[15] and diabetic retinopathy is rising.[1;16] It is a leading cause of blindness in the population of working-aged adults.[17] In the Netherlands, between 2007 and 2020, the number of patients with diabetic retinopathy is expected to increase by 42% to over one million.[17] Diabetic retinopathy causes damage to small blood vessels in the retina after prolonged periods of high blood sugar levels. Initially, this may stay unnoticed, but sudden deterioration can occur which may lead to central vision loss (caused by macula edema), large blind spots, or even blindness as a result of traction of the retina caused by pathologic new vessel formation. Timely treatment can prevent (further) visual loss, emphasizing the importance of preventive screening.[18] However, damage that has already occurred is irreversible, leaving visual rehabilitation as the only treatment option.

Similar to diabetic retinopathy, glaucoma also affects younger age groups. Glaucoma entails several disorders characterized by damage of the optic nerve due to either an increased pressure or insufficient perfusion of the optic disc inside the eye. There is no treatment which reverses the vision loss, but medication lowering the eye pressure can stop further damage. However, peripheral vision is usually affected, frequently causing problems with mobility, e.g. when crossing the street.[19]

Impact of low vision

Having a visual impairment has a major impact on functioning in daily life. Persons with low vision experience more difficulty performing (instrumental) activities of daily living without help,[20-23] causing these patients to be more dependent on others. Examples of (frequently) reported problems are related to reading and watching TV (e.g., [24-29]), as well as to mobility. Also, visually impaired patients are at greater risk for falls and fractures[30] and their increased fear of falling may lead to avoidance of activities.[31] In addition, they are reported to be more restricted in their participation in society[27;32] (such as employment and recreational activities), and to have a higher prevalence of loneliness.[33;34] Moreover, they have a higher risk of depression[35-38] and have high levels of emotional distress.[23;39] In addition, many studies showed that visually impaired people have a lower quality of life.[23;40-42] A study by Langelaan et al., for instance, revealed that Dutch adult persons with a visual impairment had a lower quality of life compared to a healthy reference group, as well as compared to conditions such as hearing impairment and diabetes type 2.[40] Moreover, since most persons with low vision are elderly, co-morbidity is often reported. Van Nispen et al. (2009) showed that musculoskeletal conditions, COPD/asthma and stroke were predictors for a relatively rapid decrease in health-related quality of life in visually impaired persons.[43] Patients with co-morbidity may need to overcome additional barriers for successful rehabilitation. Also, because usual rehabilitation strategies may not suit the patient´s condition (e.g., a patient with osteoarthritis may not be able to participate in an intensive mobility program or to use a handhold magnifier) the effect of rehabilitation may be impaired.[44]

In 1999, the WHO initiated the Global Initiative of the Elimination of Avoidable Blindness, also known as “Vision 2020: the Right to Sight”, to eliminate the main causes of avoidable blindness by the year 2020.[3] This initiative facilitates the planning, development and implementation of sustainable national eye care programs which should best be achieved by integrating an equitable, sustainable, comprehensive eye care system into every national health system. As part of this global initiative, in 2003, “VISION 2020 Netherlands” was launched to serve as a platform to improve the collaboration and coordination of those involved with preventive eye care (e.g., screening programs), treatment, research, education and rehabilitation in the field of eye care.[45]

Rehabilitation for low vision patients with visual impairment in the Netherlands

The goal of low vision rehabilitation is to enhance ability with the patient´s remaining vision. In the Netherlands, several options are available for assistance of visually impaired patients. First, there are several optometric services; these offer monodisciplinary care and are usually located at hospitals and opticians. Optometrists assess the visual functioning of the visually impaired person by measuring refractive error, visual acuity for distance and near, evaluation of the binocular vision, reading ability, and (if indicated) additional testing such as contrast sensitivity and color vision. Moreover, they generally ask about problems encountered in daily life and then advise the person about possible low vision aids and how to use them. They mainly prescribe optical aids (such as specific spectacles, telescopic devices and electronic visual enhancement systems), but also non-magnifying low vision aids (such as specific illumination, night vision goggles, and devices to reduce glare).[46] In case of complex needs, optometric services refer their patients to multidisciplinary care (referral may also be done directly by the ophthalmologist). Most larger Dutch cities have a Multidisciplinary Rehabilitation Center (MRC) for visually impaired persons which, in addition to optometric services, offer outpatient multidisciplinary care. Although the intake procedure differs between sites, professionals and patients, the patients generally receive an intake consultation to assess their rehabilitation needs directly after enrolment. This conversation is usually followed by a visual function examination by a low vision specialist (a clinical physicist or an optometrist) at the MRC. Ophthalmic information is received from the ophthalmologist and, if necessary, additional medical information is requested from other medical specialists (e.g., general practitioner, neurologist). For some patients, additional and more specific investigations can be recommended by the professional intaker or by the low-vision specialist based on the visual function examination, depending on the individual needs of the patient. Examples of additional investigations are exploration of possible rehabilitation needs concerning computer use, an employment-related social work investigation, an occupational investigation, or a psychosocial investigation. MRCs offer rehabilitation programs and additional care in several ways. Low vision therapists train low vision patients to use residual vision. Occupational therapists train patients in the use of low vision devices and in performing activities of daily living such as computer training, mobility or orientation training, cooking training, or by means of advice on environmental changes (e.g., illumination, placing tactile markers on stove or washing machine). In addition, psychologists and social workers provide group or individual counseling and psychosocial care. Moreover, other trainers provide services in, for example, creative skills, art and music groups, or in training braille.

Although the insurance structure is expected to change in 2014, monodisciplinary and multidisciplinary care has been largely financed by the Exceptional Medical Expenses Act) known in the Netherlands as the *Algemene Wet Bijzondere Ziektekosten*. Ophthalmologists, general practitioners and other physicians can refer patients to low vision rehabilitation services. In 2004, the Dutch Ophthalmic Society (known as *Nederlands Oogheelkundig Genootschap; NOG*) developed an evidence-based guideline on the referral of persons with irreversible vision loss to low-vision rehabilitation.[47] This guideline was updated in

2011.[48] It is recommended that patients with a visual acuity <0.5 and/or a reading acuity of <0.25, and/or visual field defects <30 degrees of fixation, and/or other severe field defects (e.g., hemionopsia) should be referred to low-vision rehabilitation in case vision-related problems in daily life cannot be addressed by interventions in standard ophthalmic care, but can (potentially) be solved by visual rehabilitation. Patients may also contact these services on their own initiative.

International Classification of Functioning, Disability and Health (ICF)

In 2001, the WHO developed the International Classification of Functioning, Disability and Health (ICF)[49] to replace the earlier International Classification of Impairments, Disabilities and Handicaps (or ICIDH),[2;50] This renewed ICF has placed the notions of ´health' and ´disability´ in a new light. The ICF provides an important international taxonomy for classifying and measuring functions, disabilities and health with standard concepts and terminology. The ICF is a comprehensive biopsychosocial framework[51] which classifies health and health-related domains (irrespective of their causes) based on three different perspectives: the body, individual, and societal. The first perspective ('body': the human as an organism) concerns the functions and anatomical attributes with consideration of potential disorders; this perspective is divided into two separate classifications: 'Body structures' and 'Body functions'. The second perspective ('individual': human actions) concerns activities with a focus on potential activity limitations. The third perspective ('societal': involvement in society) focuses on participation and deals with potential restrictions in participation. The second and third perspective were taken together to be classified by the nine 'Activity and Participation' domains: (1) learning and applying knowledge; general tasks and demands (2); communication (3); mobility (4); self-care (5); domestic life (6); interpersonal interactions and relationships (7); major life areas (8); community, social, and civic life (9). The ICF framework is shown in Figure 1.

Within the ICF, 'functioning' is an umbrella term which encompasses all body functions, activities and participation, whilst 'disability' is used to refer to the corresponding impairments, activity limitations or participation restrictions. Disability depends not only on the individual's health condition, but also on 'contextual factors'. These can be expressed by 'personal factors' (such as personal characteristics, history or preferences) as well as 'external factors' of the environment in which the individual lives (e.g., the physical, social and attitudinal environment).

From the perspective of the ICF, disorders of bodily structures lead to impairments in bodily function (e.g., disorders in the visual system result in impairments in 'seeing functions'). This will usually, but not necessarily, result in disabilities in activities and participation, as disability also depends on the interaction of a person's health characteristics and their contextual factors. In rehabilitation research, the measurement of disability is an important topic. As a visual impairment has a major impact on functioning in daily living, measuring disability in patients with low vision is best described in terms of activity limitations and participation restrictions.[52] The nature and level of disability can be measured in several ways, e.g., by using observations, performance testing or self-report.

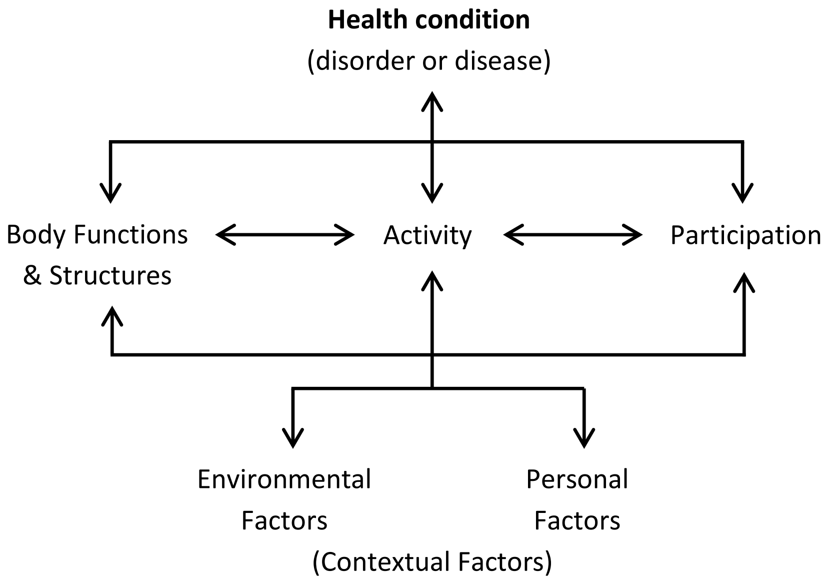

Figure 1. The International Classification of Functioning, Disability and Health (ICF) framework.

The value and application of the ICF in rehabilitation medicine has been widely discussed.[52] The ICF classification provides an interesting structure to describe the functioning of an individual and investigate rehabilitation needs. However, it is not an assessment tool. In addition, because the ICF is a general model, it is not specifically based on experiences of visually impaired people. Activities that represent the most detailed level of the 'Activities and Participation' domains of the ICF are described in general terms, for instance, "cleaning living area", or "washing and drying clothes and garments". A general activity, such as using public transportation, involves many specific cognitive and visual motor activities; however, many specific activities that are problematic for visually impaired people are not included in the ICF. To assess the actual problems of visually impaired persons, a more thorough and specific assessment is needed. For example, “Recognizing the right bus” is a typical problem for visually impaired people but this specific item is not included in the ‘Activities and Participation’ domains of the ICF structure. However, it is important to know why someone is not able to, for example, “use public motorized transportation” which is included in the ‘Activity and Participation’ domains of the ICF. To develop an assessment tool for visual rehabilitation needs, the specific activities and participation need to be examined more specifically.

Patient-centered care

Over the last decades, the focus of medical care has tended to evolve from ‘cure’ towards ‘care’ - and rehabilitation plays a prominent place in this trend. To achieve the best possible quality of life, low-vision rehabilitation should deliver personalized care, which should take into account the individual needs of the patient.[53] Investigating these needs is essential for delivering personalized care. Accordingly, the concept of ‘patient-centered medicine’ has gained increasing attention[54-60] with the general opinion that patients should be involved in clinical decision-making. It is suggested that shared decision-making is particularly suitable for long-term decisions, especially for patients with a chronic impairment and when the intervention involves more than one session.[61] Decision-making is often expressed in goal-setting approaches,[62-64] because these are reported to increase the patient’s progress in rehabilitation[65] and to foster adherence to physicians’ recommendations.[66] Clearly, in patient-centered medicine patients have to be involved in formulating these goals. Based on these insights, the updated version of the evidence-based guideline on the referral of persons with irreversible vision loss to low-vision rehabilitation now recommends that decisions on future treatment should be based on a shared decision-making process.[48] Hence, rehabilitation medicine needs an instrument that helps investigate rehabilitation needs from the patient’s perspective and serves as input for a shared-decision making process.

Measuring rehabilitation outcomes

In a recent systematic review by Binns et al.[67] 47 different outcome measures for assessing the effectiveness of rehabilitation services were included. This implies there is still little consensus on how to evaluate the effect of rehabilitation. Some studies use measures such as near visual acuity (with and without low vision aids (e.g., [68])). Others focus on more specific functional measures such as reading (e.g., speed or accuracy),[69;70] or on more global functional measures such as measuring activities of daily living by questionnaires: e.g., studies using the Visual Function Questionnaire (VFQ),[71] Perceived security in performing Activities of Daily Living,[72] the 48-item Veterans' Affairs Low Vision Visual Function Questionnaire,[73] and the Visual Function Questionnaire (VF-14).[74] As the ultimate goal of low vision rehabilitation is to improve quality of life, other studies aim to investigate the effectiveness using this concept. Several vision-related quality of life questionnaires were developed for this purpose, e.g., Low Vision Quality-Of-Life questionnaire (LVQOL),[75] the Impact of Vision Impairment (IVI) profile,[76;77] the Vision Quality-of-life Core Measure (VCM1) and the National Eye Institute Visual Function Questionnaire (NEI-VFQ)[78;79] and were evaluated for their psychometric properties (e.g., the systematic review by de Boer et al.[80]). In addition, more global health-related quality of life measures are used for this purpose, e.g., the EuroQol five-dimension questionnaire (Q-5D)[81-83] or the 36-item Medical outcomes Short-Form (SF-36),[84-86] as well as measures that represent psychological wellbeing, such as adaptation to vision loss (e.g., the Adaptation to Age-Related Visual Loss (AVL) scale[87;88]) or depression (e.g., the Centre for Epidemiological Studies Depression Scale (CES-D)[89]).

Most measurement instruments have been used as global outcomes of rehabilitation or to measure specific domains of rehabilitation, such as mobility, adjustment, or reading/fine work. However, they are not suitable to investigate the full range of individual rehabilitation needs. In addition, many specific rehabilitation goals of patients (e.g., "using public transport" or "daily shopping") and their associated tasks (e.g., "read departure/arrival times" and "recognize the right stop" or "read the 'best before' date" and "find your way in a shop") are not specifically represented by the constructs of the available questionnaires. This implies that it is very complicated to investigate specific rehabilitation needs, and to create an appropriate and corresponding rehabilitation plan. Moreover, to evaluate 'patient-centered' care, ideally, the effect measurements should focus on the goals the patient wanted to target in the rehabilitation trajectory. As these questionnaires tend to ignore the individual needs of the patient, these questionnaires are less suitable to evaluate the effectiveness of rehabilitation for individuals.

Need for a new assessment tool

Due to the increasing number of patients with visual impairment, there is an increasing need for more efficient care. In addition, due to increasing medical costs, insurance companies and MRCs are aware of the need for more evidence-based care. However, until recently, during the intake process at MRCs, the rehabilitation needs of the patient were not investigated in a structured way. Such an unstructured system implies that evaluating the effectiveness of rehabilitation is also problematic.

This unstructured way of investigating the rehabilitation needs of visually impaired people not only hampers evaluation, but also increases the risk that only the most prominent disability emerges during the intake procedure, instead of the whole spectrum of problems. Also, there is a risk that the content of rehabilitation depends on the qualities and/or individual preferences of the intake assessor, and that rehabilitation services are driven by supply and not by the demand of the client. These risks are even higher when patients are not systematically involved in creating a rehabilitation program; this can result in the rehabilitation trajectory being longer and more difficult than required.

Based on these considerations, around the year 2006, MRCs indicated they wanted to change their intake and evaluation procedure. In order to deliver better personalized care, they needed an instrument to investigate the full range of possible needs in a systematic way and also from the patient's perspective. In addition, this would allow them to acquire a baseline measurement so that the effect of rehabilitation for individual goals could be determined using the same instrument. Finally, as the use of the ICF in rehabilitation medicine is increasing, the systematic approach should preferably be nested within the ICF. This instrument would serve as a means to improve (medical) communication between, e.g., providers, researchers, patients, policymakers, and insurance companies. However, no such instrument was available in the Netherlands.

The Activity Inventory

In the USA, Massof et al.[90-95] presented an interesting concept to systematically investigate the rehabilitation needs of visually impaired persons from the patient's perspective. They created the Activity Inventory (AI) which was specifically developed for visually impaired persons. The AI has a hierarchical structure in which 'tasks' (specific cognitive and motor activities, e.g., 'reading a recipe') that serve a common purpose are nested under 'goals' (e.g., 'daily meal preparation'). These goals, in turn, were classified by their 'objectives' (i.e., 'daily living', 'recreation', 'social interactions', 'education', 'vocation'). The AI rates the importance and difficulty of goals and, for important goals, the difficulty of underlying tasks. This concept is useful to investigate and prioritize rehabilitation goals in the intake phase and, simultaneously, to provide more detailed insight into the associated problematic tasks. Moreover, by quantifying rehabilitation needs of a patient, the progress of the patient can be monitored thereby allowing evaluation of rehabilitation outcome.

The items in the inventory were compiled from a review of functional history interviews based on 3,200 patients earlier seen at the Lions Low Vision Service.[93] The 30-45 minute interviews were obtained by clinical social workers who were specialized in low vision. The 24 most 'frequently cited' goals were included in the AI.[90] In addition, the AI was extended after being administered (in a pilot study) to an elderly low vision population by asking them to identify additional goals and tasks of relevance to them, that were not included in the original list.[90] This resulted in a modification of the AI which then consisted of 41 goals and 337 (instead of about 200) tasks.[90;95] In 2006, Massof et al. reported on an updated version of the AI (personal communication, unpublished) which included additional goals such as 'Driving'; however, the objectives 'Education' and 'Vocation' were not yet fully worked out.

Although MRCs were interested in using the concept of the AI, because it was developed in the USA it was not immediately applicable to the Dutch situation. Common Dutch topics such as 'using public transportation´ or 'riding a bicycle' were not fully covered. Moreover, the AI was not nested in the ICF. To make the AI suitable for assessing and evaluation rehabilitation needs in Dutch visually impaired persons, considerable adaptations were needed.

Aim and outline of the thesis

The aim of this thesis is to develop a valid, reliable and feasible tool nested in the ICF framework to investigate and evaluate rehabilitation needs of visually impaired persons. In addition, this new tool will be used to investigate rehabilitation needs of visually impaired persons entering an MRC and to evaluate these needs over time.

In **Chapter 2,** the first step in the developmental process of a new questionnaire (Dutch ICF Activity Inventory: the D-AI) is described. The original Activity Inventory was used as input. In order to extend and adapt the questionnaire (and provide good face and content validity), relevant topics for the new questionnaire were collected by reviewing literature, studying patient records, and conducting focus group discussions with rehabilitation professionals and visually impaired persons.

Chapter 3 presents a pilot study performed to test the feasibility of the D-AI using a computer-assisted telephone interview. Moreover, it was examined whether the most relevant topics were covered by the D-AI and whether all questions and answer categories were clear and satisfactory. Patients and assessors were asked about their perceptions of and experiences with the assessment of the D-AI.

Chapter 4 describes to what extent the rehabilitation needs were identified using the structured intake based on the D-AI, and using the regular ‘unstructured’ intake in the MRC. The patient files were studied to better understand and clarify possible discrepancies in the rehabilitation needs identified, to study the strengths/weaknesses of the D-AI, and to make further improvements.

The study described in **Chapter 5** aims to elucidate the underlying factor structure of the tasks underneath the goals in the D-AI. In addition, detailed information on the psychometric properties (i.e., test re-test reliability and internal consistency) for individual goals are provided. Based on these results, plus additional feedback from patients, assessors and consensus-based discussions, adaptations were made to the D-AI. For this purpose the D-AI was assessed within a large sample of visually impaired persons who were recently enrolled at an MRC.

Chapter 6 investigates the longitudinal outcomes of rehabilitation (4 and 12 months after enrolment) of the high priority goals in the ICF domain ‘Learning and applying knowledge’ (i.e., ‘Reading’, ‘Writing’ and ‘Watching TV’), as measured with the D-AI. In addition, interventions related to these goals mentioned by self-report and documented in the patient files of Dutch MRCs were investigated. Moreover, the outcomes measured by the D-AI and standardized outcomes were examined to provide more insight into the (longitudinal) interpretation of the D-AI.

In **Chapter 7** the longitudinal energy balance and mental health outcomes are studied in relation to rehabilitation programs followed in Dutch MRCs (4 and 12 months after enrolment) measured with the three D-AI goals ‘Handle feelings’, ‘Acceptance’, and ‘Feeling fit’. In addition, attention was paid to the (longitudinal) interpretation of the concept of mental health and energy balance by studying related constructs.

Chapter 8 describes and interprets the results and experiences with the newly developed instrument, and provides insight into how to use the D-AI in clinical practice. For this purpose, an implementation pilot was started in which the instrument was used as a standard intake instrument for visually impaired persons entering an MRC.

Chapter 9 summarizes the various steps in the D-AI development process. In addition, the main findings of each study will be addressed.

Finally, **Chapter 10**, places the findings in this thesis into context. Moreover, methodological limitations of the studies are addressed and implications for clinical practice and future research are discussed.

References

1 Keunen JEE, Verezen CA, Imhof SM, van Rens GHMB, Asselbergs MB, Limburg JJH. [Increase in the demand for eye-care services in the Netherlands 2010-2020]. Ned Tijdschr Geneeskd 2011;155:A3461.
2 World Health Organization. The ICD-10 classification of mental and behavioural disorders: diagnostic criteria for research. World Health Organization, 1993.
3 Resnikoff S, Pascolini D, Etya'ale D, Kocur I, Pararajasegaram R, Pokharel GP, Mariotte SP. Global data on visual impairment in the year 2002. Bulletin of the World Health Organization 2004;82:844-851.
4 Pascolini D, Mariotti SP. Global estimates of visual impairment: 2010. Br J Ophthalmol 2012;96:614-618.
5 Foster A, Resnikoff S. The impact of Vision 2020 on global blindness. Eye 2005;19:1133-1135.
6 Buch H, Vinding T, La Cour M, Appleyard M, Jensen GB, Vesti Nielsen N. Prevalence and causes of visual impairment and blindness among 9980 Scandinavian adults: the Copenhagen City Eye Study. Ophthalmology 2004;111:53-61.
7 Congdon N, O'Colmain B, Klaver CCW, Klein R, Muňoz B, Friedman DS, Kempen J, Taylor HR, Mitchell P, Eye Diseases Prevalences Research Group. Causes and prevalence of visual impairment among adults in the United States. Arch Ophthalmol 2004;122:477-485.
8 Limburg H. Epidemiologie van visuele beperkingen en een demografische verkenning. [Epidemiology of visual disabilities and a demographic investigation];Report commissioned by the Netherlands organization for health research and development (ZonMw) and the InSight Society, 2007.
9 de Boer MR, Langelaan M, Jansonius NM, van Rens GHMB. Evidence-based guidelines on the referral of visually impaired persons to low vision services. Eur J Ophthalmol 2005;15:400-406.
10 Kocur I, Resnikoff S. Visual impairment and blindness in Europe and their prevention. Br J Ophthalmol 2002;86:716-722.
11 Taylor HR, Keeffe JE, Vu HT. Wang JJ, Rochtchina E, Pezullo ML, Mitchell P. Vision loss in Australia. Med J Aust 2005;182:565-568.
12 Klaver CCW, Wolfs RCW, Vingerling JR, Hofman A, de Jong PTVM. Age-specific prevalence and causes of blindness and visual impairment in an older population: the Rotterdam Study. Arch Ophthalmol 1998;116:653.
13 Seddon JM, Reynolds R, Rosner B. Associations of smoking, body mass index, dietary lutein, and the LIPC gene variant rs10468017 with advanced age-related macular degeneration. Mol Vis 2010;16:2412.
14 Seddon J, Fong D, West SK, Valmadrid CT. Epidemiology of risk factors for age-related cataract. Surv Ophthalmol 1995;39:323-334.
15 Shaw JE, Sicree RA, Zimmet PZ. Global estimates of the prevalence of diabetes for 2010 and 2030. Diabetes Res Clin Pre 2010;87:4-14.
16 Yau JW, Rogers SL, Kawasaki R, Lamoureux EL, Kowalski JW, Bek T, Chen SJ, Dekker JM, Fletcher A, Grauslund J, Haffner S, Hamman RF, Ikram MK, Kayama T, Klein BE, Klein R, Krishnaiah S, Mayurasakorn K, O'Hare JP, Orchard TJ, Porta M, Rema M, Roy MS, Sharma T, Shaw J, Taylor H, Tielsch JM, Varma R, Wang JJ, Wang N, West S, Xu L,

Yasuda M, Zhang X, Mitchell P, Wong TY; Meta-Analysis for Eye Disease (META-EYE) Study Group. Global Prevalence and Major Risk Factors of Diabetic Retinopathy. Diabetes Care 2012;35:556-564.
17 Kempen G, Ballemans J, Ranchor A, van Rens G, Zijlstra G. The impact of low vision on activities of daily living, symptoms of depression, feelings of anxiety and social support in community-living older adults seeking vision rehabilitation services. Qual Life Res 2011;11:1405-1411
18 Rodbard HW, Blonde L, Braithwaite SS et al. AACE Diabetes Mellitus Clinical Practice Guidelines Task Force. American Association of Clinical Endocrinologists medical guidelines for clinical practice for the management of diabetes mellitus. Endocr Pract 2007;13:1-68.
19 Cheong AMY, Geruschat DR, Congdon N. Traffic gap judgment in people with significant peripheral field loss. Optom Vis Sci 2008;85:26-36.
20 Berger S, Porell F. The association between low vision and function. J Aging Health 2008;20:504-525.
21 Rubin GS, Bandeen-Roche K, Huang GH et al. The association of multiple visual impairments with self-reported visual disability: SEE project. Invest Ophthalmol Vis Sci 2001;42:64-72.
22 Tabrett DR, Latham K. Factors influencing self-reported vision-related activity limitation in the visually impaired. Invest Ophthalmol Vis Sci 2011;52:5293-5302.
23 Williams RA, Brody BL, Thomas RG, Kaplan RM, Brown SI. The psychosocial impact of macular degeneration. Arch Ophthalmol 1998;116:514-520.
24 Burggraaff MC, van Nispen RMA, Knol DL, Ringens PJ, van Rens GHMB. Randomized Controlled Trial on the Effects of CCTV Training on Quality of Life, Depression, and Adaptation to Vision Loss. Invest Ophthalmol Vis Sci 2012;53:3645-3652.
25 Chung STL. Improving reading speed for people with central vision loss through perceptual learning. Invest Ophthalmol Vis Sci 2011;52:1164-1170.
26 Fok D, Polgar JM, Shaw L, Jutai JW. Low vision assistive technology device usage and importance in daily occupations. Work 2011;39:37-48.
27 Lamoureux EL, Hassell JB, Keeffe JE. The determinants of participation in activities of daily living in people with impaired vision. Am J Ophthalmol 2004;137:265-270.
28 Watching Television by Visually Impaired Elderly People. Vision 2008 Montréal, Canada, 2008.
29 Woods RL, Nandhini P. Television, computer and portable display device use by people with central vision impairment. Ophthal Physl Opt 2011;31:258-274.
30 de Boer MR, Pluijm SMF, Lips P, Moll AC, Völker-Dieben HJ, Deeg DJ, van Rens GH. Different aspects of visual impairment as risk factors for falls and fractures in older men and women. J Bone Miner Res 2004;19:1539-1547.
31 Kempen GIJM, van Haastregt JCM, McKee KJ, Delbaere K, Zijlstra GAR. Socio-demographic, health-related and psychosocial correlates of fear of falling and avoidance of activity in community-living older persons who avoid activity due to fear of falling. BMC Public Health 2009;9:170.

32 Alma MA, van der Mei SF, Melis-Dankers BJM, van Tilburg TG, Groothoff JW, Suurmeijer TPBM. Participation of the elderly after vision loss. Disabil Rehabil 2011;33:63-72.
33 Verstraten, P.F.J., Brinkmann, W.L.J.H, Stevens, N.L., Schouten, J.S.A.G. Loneliness, adaptation to vision impairment, social support and depression among visually impaired elderly. International Congress Series 2005; 1282: 317-321.
34 Alma MA, Van der Mei SF, Feitsma WN, Groothoff JW, Van Tilburg TG, Suurmeijer TPBM. Loneliness and self-management abilities in the visually impaired elderly. J Aging Health 2011;23:843-861.
35 Kempen GIJM, Ballemans J, Ranchor AV, van Rens GHMB, Zijlstra GAR. The impact of low vision on activities of daily living, symptoms of depression, feelings of anxiety and social support in community-living older adults seeking vision rehabilitation services. Quality of Life Research 2012;1-7.
36 Horowitz A, Reinhardt JP, Kennedy GJ. Major and subthreshold depression among older adults seeking vision rehabilitation services. Am J Geriatr Psychiatry 2005;13:180-187.
37 Evans JR, Fletcher AE, Wormald RPL. Depression and anxiety in visually impaired older people. Ophthalmology 2007;114:283-288.
38 Brody BL, Gamst AC, Williams RA, Smith AR, Lau PW, Dolnak D, Rapaport MH, Kaplan RM, Brown SI. Depression, visual acuity, comorbidity, and disability associated with age-related macular degeneration. Ophthalmology 2001;108:1893-1900.
39 Rees G, Tee HW, Marella M, Fenwick E, Dirani M, Lamoureux EL. Vision-specific distress and depressive symptoms in people with vision impairment. Invest Ophth Vis Sci 2010;51:2891-2896.
40 Langelaan M, de Boer MR, van Nispen RMA, Wouters B, Moll AC, van Rens GHMB. Impact of visual impairment on quality of life: a comparison with quality of life in the general population and with other chronic conditions. Ophthalmic Epidemiol 2007;14:119-126.
41 Seland JH, Vingerling JR, Augood CA, Bentham G, Chakravarthy U, deJong PT, Rahu M, Soubrane G, Tomazzoli L, Topouzis F, Fletcher AE. Visual impairment and quality of life in the older European population, the EUREYE study. Acta Ophthalmol 2011;89:608-613.
42 Sprangers MA, de Regt EB, Andries F, van Agt HM, Bijl RV, de Boer JB, Foets M, Hoeymans N, Jacobs AE, Kempen GI, Miedema HS, Tijhuis MA, de Haes HC. Which chronic conditions are associated with better or poorer quality of life? J Clin Epidemiol 2000;53:895-907.
43 van Nispen RMA, de Boer MR, Hoeijmakers JGJ, Ringens PJ, van Rens GHMB. Co-morbidity and visual acuity are risk factors for health-related quality of life decline: five-month follow-up EQ-5D data of visually impaired older patients. Health Qual Life Outcomes 2009;7:18.
44 van Nispen RMA, Hoeijmakers JGJ, de Boer MR, Ringens PJ, van Rens GHMB. Agreement between self-reported co-morbidity of visually impaired older patients and reports from their general practitioners. Visual Impairment Research 2008;10:49-56.
45 Limburg H, den Boon JM, Hogeweg M, Gevers RJ, Keunen JE, Ten Hove GT. Avoidable visual impairment in The Netherlands: the project"

Vision 2020 Netherlands" of the World Health Organization. Ned Tijdschr Geneeskd 2005;149:577-582.
46 Verezen CA. Eccentric Viewing Spectacles, Including an Introduction in Low Vision Rehabilitation. Thesis, 2008.
47 Nederlands Oogheelkundig Gezelschap. Richtlijn Verwijzing van slechtzienden en blinden [Guidelines for the referral of the visually impaired and blind]. de Boer MR, Jansonius N, Langelaan M, van Rens GHMB (red). Van Zuiden Communications bv. Alphen aan de Rijn. 2004.
48 van Rens G, Vreeken HL, van Nispen RMA. Richtlijn visusstoornissen, revalidatie en verwijzing, 2011.
49 World Health Organisation. International classification of functioning, disability and health. WHO, Geneve, 2001.
50 World Health Organization. International Classification of Impairments, Disabilities, and Handicaps: A Manual of Classification Relating to the Consequences of Disease. Geneva (Switzerland): ERIC Clearinghouse, Washington, 1980.
51 Waddell G, Burton AK. Concepts of rehabilitation for the management of common health problems. The Stationery Office, United Kingdom, 2004.
52 Heerkens YF, van Ravensberg CD. Toepassingsmogelijkheden van de multiprofessionele International Classification of Functioning, Disability and Health (ICF) in de paramedische zorg [Application of the multiprofessional International Classification of Functioning, Disability and Health (ICF) in paramedical care]. Amersfoort: Nederlands Paramedisch Instituut (NPi), 2007.
53 Chouchane L, Mamtani R, Dallol A, Sheikh JI. Personalized medicine: a patient-centered paradigm. J Transl Med 2011;9:206.
54 de Haes H, Bensing J. Endpoints in medical communication research, proposing a framework of functions and outcomes. Patient Educ Couns 2009;74:287-294.
55 Leach E, Cornwell P, Fleming J, Haines T. Patient centered goal-setting in a subacute rehabilitation setting. Disabil Rehabil 2010;32:159-172.
56 Pollock N. Client-centered assessment. Am J Occup Ther 1993;47:298-301.
57 Siegert RJ, McPherson KM, Taylor WJ. Toward a cognitive-affective model of goal-setting in rehabilitation: is self-regulation theory a key step? Disabil Rehabil 2004;26:1175-1183.
58 Bensing J. Bridging the gap. The separate worlds of evidence-based medicine and patient-centered medicine. Patient Educ Couns 2000;39:17-25.
59 Turner-Stokes L. Politics, policy and payment-facilitators or barriers to person-centred rehabilitation? Disabil Rehabil 2007;29:1575-1582.
60 Battersby M, Von Korff M, Schaefer J, Davis C, Ludman E, Greene SM, Parkerton M, Wagner EH. Twelve evidence-based principles for implementing self-management support in primary care. Jt Comm J Qual Patient Saf 2010;36:561-570.
61 Joosten EAG, DeFuentes-Merillas L, de Weert GH, Sensky T, van der Staak CPF, de Jong CAJ. Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status. Psychother Psychosom 2008;77:219-226.

62 Hurn J, Kneebone I, Cropley M. Goal setting as an outcome measure: A systematic review. Clin Rehabil 2006;20:756-772.
63 Rushton PW, Miller WC. Goal attainment scaling in the rehabilitation of patients with lower-extremity amputations: a pilot study. Arch Phys Med Rehabil 2002;83:771-775.
64 Schulman-Green DJ, Naik AD, Bradley EH, McCorkle R, Bogardus ST. Goal setting as a shared decision making strategy among clinicians and their older patients. Patient Educ Couns 2006;63:145-151.
65 Rockwood K, Joyce B, Stolee P. Use of goal attainment scaling in measuring clinically important change in cognitive rehabilitation patients. J Clin Epidemiol 1997;50:581-588.
66 Bogardus STJ, Bradley EH, Williams CS, Maciejewski PK, Gallo WT, Inouye SK. Achieving goals in geriatric assessment: role of caregiver agreement and adherence to recommendations. J Am Geriatr Soc 2004;52:99-105.
67 Binns AM, Bunce C, Dickinson C, Harper R, Tudor-Edwards R, Woodhouse M, Linck P, Suttie A, Jackson J, Lindsay J, Wolffsohn J, Hughes L, Margrain TH. How effective is low vision service provision? A systematic review. Surv Ophthalmol 2012;57:34-65.
68 Ryan B, White S, Wild J, Margrain TH. The newly established primary care based Welsh Low Vision Service is effective and has improved access to low vision services in Wales. Ophthal Physl Opt 2010;30:358-364.
69 Burggraaff MC, van Nispen RMA, Hoeben FP, Knol DL, van Rens GHMB. Randomized controlled trial on the effects of training in the use of closed-circuit television on reading performance. Invest Ophth Vis Sci 2012;53:2142-2150.
70 Goodrich GL, Kirby J, Wood J, Peters L. The Reading Behavior Inventory: An Outcome Assessment Tool. J Vis Impair Blin 2006;100:164-168.
71 Scott IU, Smiddy WE, Schiffman J, Feuer WJ, Pappas CJ. Quality of life of low-vision patients and the impact of low-vision services. Am J Ophthalmol 1999;128:54-62.
72 Eklund K, Sonn U, hlin-Ivanoff S. Long-term evaluation of a health education programme for elderly persons with visual impairment. A randomized study. Disabil Rehabil 2004;26:401-409.
73 Stelmack JA, Tang XC, Reda DJ, Rinne S, Mancil RM, Massof RW. Outcomes of the Veterans Affairs Low Vision Intervention Trial (LOVIT). Arch Ophthalmol 2008;126:608-617.
74 Steinberg EP, Tielsch JM, Schein OD, Javitt JC, Sharkey P, Cassard SD, Legro MW, Diener-West M, Bass EB, Damiano AM, et al. The VF-14. An index of functional impairment in patients with cataract. Arch Ophthalmol 1994;112:630-638.
75 Wolffsohn JS, Cochrane AL. Design of the low vision quality-of-life questionnaire (LVQOL) and measuring the outcome of low-vision rehabilitation. Am J Ophthalmol 2000;130:793-802.
76 Hassell JB, Weih LM. A measure of handicap for low vision rehabilitation: the impact of vision impairment profile. Clin Experiment Ophthalmol 2000;28:156-161.

77 Weih LM, Hassell JB, Keeffe J. Assessment of the impact of vision impairment. Invest Ophthalmol Vis Sci 2002;43:927-935.
78 Mangione CM, Berry S, Spritzer K, Janz NK, Klein R, Owsley C, Lee PP. Identifying the content area for the 51-item National Eye Institute Visual Function Questionnaire: results from focus groups with visually impaired persons. Arch Ophthalmol 1998;116:227-233.
79 Mangione CM, Lee PP, Gutierrez PR, Spritzer K, Berry S, Hays RD. Development of the 25-item national eye institute visual function questionnaire. Arch Ophthalmol 2001;119:1050.
80 de Boer MR, Moll AC, de Vet HCW, Terwee CB, Volker-Dieben HJM, van Rens GHMB. Psychometric properties of vision-related quality of life questionnaires: a systematic review. Ophthalmic Physiol Opt 2004;24:257-273.
81 Rabin R, de Charro F. EQ-5D: a measure of health status from the EuroQol Group. Ann Med 2001;33:337-343.
82 EuroQol Group. EQ-5D User guide. Euroqol Business Management, Rotterdam, 1996
83 de Boer MR, Twisk J, Moll AC, Volker-Dieben HJM, de Vet HCW, van Rens GHMB. Outcomes of low-vision services using optometric and multidisciplinary approaches: a non-randomized comparison. Ophthalmic Physiol Opt 2006;26:535-544.
84 McHorney CA, War Jr JE, Lu JFR, Sherbourne CD. The MOS 36-item Short-Form Health Survey (SF-36): III. Tests of data quality, scaling assumptions, and reliability across diverse patient groups. Med Care 1994;40-66.
85 McHorney CA, Ware Jr JE, Raczek AE. The MOS 36-Item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. Med Care 1993;247-263.
86 Ware Jr JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36): I. Conceptual framework and item selection. Med Care 1992;473-483.
87 Horowitz A, Reinhardt JP. Development of the adpatation to age-related vision loss scale. J Visual Impair Blin 1998;92:30-41.
88 Horowitz A, Reinhardt JP, Raykov T. Development and Validation of a Short-Form Adaptation of the Age-Related Vision Loss Scale: The AVL12. J Visual Impair Blin 2007;101:146-159.
89 Radloff LS. The CES-D Scale: A Self-Report Depression Scale for Research in the General Population. Appl Psych Meas 1977;1:385-401.
90 Massof RW. A systems model for low vision rehabilitation. I. Basic concepts. Optom Vis Sci 1995;72:725-736.
91 Massof RW. A systems model for low vision rehabilitation. II. Measurement of vision disabilities. Optom Vis Sci 1998;75:349-373.
92 Massof RW, Rubin GS. Visual function assessment questionnaires. Surv Ophthalmol 2001;45:531-548.
93 Massof RW, Hsu CT, Baker FH, Barnett GD, Park WL, Deremeik JT, Rainey C, Epstein C. Visual disability variables. I: the importance and difficulty of activity goals for a sample of low-vision patients. Arch Phys Med Rehabil 2005;86:946-953.

94 Massof RW, Hsu CT, Baker FH, Barnett GD, Park WL, Deremeik JT, Rainey C, Epstein C. Visual disability variables. II: The difficulty of tasks for a sample of low-vision patients. Arch Phys Med Rehabil 2005;86:954-967.

95 Massof RW, Ahmadian L, Grover LL, Deremeik JT, Goldstein JE, Rainey C, Epstein C, Barnett GD. The Activity Inventory: an adaptive visual function questionnaire. Optom Vis Sci 2007;84:763-774.