Evaluating Disease Management Programmes in the Netherlands

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Content

Samenvatting

In het ZonMw programma 'Disease Management Chronische Ziekten' (DMCZ) zijn 22 praktijkprojecten ontwikkeld, gevolgd en geëvalueerd. Deze ZonMw-praktijkprojecten hadden een looptijd van ongeveer drie jaar. Gedurende deze periode zijn de projecten systematisch gevolgd op een aantal proces- en effectmaten en kosten-effectiviteit. De verwachting is dat disease management programma's gebaseerd op Ed Wagner's chronische zorgmodel bijdragen aan betere kwaliteit van chronische zorgverlening. Inzicht in de korte en lange termijn effecten van implementatie van dit type programma's voor verschillende chronische aandoeningen is echter nog schaars. In het kader van het onderzoek zijn in 2010, 2011 en 2012 vragenlijsten verstuurd naar alle patiënten en professionals betrokken bij de 22 diseasemanagement programma's in Nederland. De resultaten laten zien dat de kwaliteit van chronische zorgverlening elk jaar opnieuw substantieel is verbeterd. Bovendien bleken patiënten na een jaar meer te bewegen en was het aantal rokers afgenomen. Op korte termijn (na een jaar) was de fysieke en mentale kwaliteit van leven echter verslechterd. Na 2 jaar was dit beeld gunstiger en bleken de disease management programma's zowel het gezondheidsgedrag (bewegen, roken) van patiënten verbeterd te hebben als hun fysieke kwaliteit van leven. Bovendien bleek uit de registratiegegevens van de huisartsen dat er sprake was van verbeterde klinische uitkomsten. De mentale kwaliteit van leven van patiënten bleek echter verslechterd te zijn. Kijkend naar de kosteneffectiviteit zijn er geen indicaties dat er sprake is van substitutie van zorg van de tweede naar de eerstelijnszorg. Over het geheel genomen zijn de disease management programma's na twee jaar nog niet kosteneffectief. Wel zijn er verschillen gevonden tussen de disease management programma's.

De mate waarin de projecten voorbereid waren op het in praktijk brengen van het disease management programma en de daarvoor benodigde systeemveranderingen was belangrijk voor de ontwikkeling en implementatie van de projecten, evenals de flexibiliteit om gedurende het proces in te spelen op behoeften van zorgprofessionals en patiënten. De belangrijkste voorspeller van het succes van de praktijkprojecten bleek de verbeterde communicatie en coördinatie te zijn tussen professionals. Communicatie dient frequent, tijdig, accuraat en oplossingsgericht te zijn. Voor goede coördinatie zijn respect, gedeelde doelen en gedeelde kennis van belang. In de zorg voor chronisch zieke patiënten gaat het daarbij om samenwerking tussen verschillende typen professionals: huisarts, POH, diëtiste, fysiotherapeut, ergotherapeut, specialist, etc. Betere samenwerking tussen professionals met verschillende achtergronden is cruciaal om de juiste ondersteuning te bieden aan chronisch zieke patiënten en zo de kwaliteit van zorg te verbeteren.

Belangrijke vraag na het beëindigen van de financiering door ZonMw is of de disease management programma's ook geborgd worden in de praktijk. Dit blijkt inderdaad het geval te zijn. In 2013 is een selectie van de 22 disease management programma's nog een jaar langer gevolgd. De verbeteringen in kwaliteit van zorg, gezondheidsgedrag van patiënten, en fysieke kwaliteit van leven van patiënten hielden stand, maar er was nog steeds geen verbetering in de mentale kwaliteit van leven.

De resultaten laten ook zien dat kwaliteitverbeteringen tijdens zowel het eerste jaar als het tweede jaar van implementatie voorspellers zijn van borging van de disease management programma's zoals beoordeeld door de betrokken professionals.

Ook patiënten beoordelen de kwaliteit van zorg beter. Het onderzoek laat zien dat de kwaliteit van zorgverlening volgens patiënten gemiddeld genomen is verbeterd. Voor professionals zijn verbeteringen in chronische zorgverlening echter al eerder zichtbaar dan voor patiënten; denk aan het werken volgens bepaalde protocollen, gebruik maken van een (Keten) ICT-systeem, en meer samenwerken met andere professionals. Het oordeel van de betrokken professionals blijkt een voorspeller te zijn van het positievere patiënten oordeel over de kwaliteit van de zorgverlening een jaar later. Dit benadrukt het belang van kwaliteit verbetering in de zorg ook als resultaten bij patiënten nog niet zichtbaar zijn.

De rol die patiënten zelf spelen in het zorgproces is van groot belang. In de disease management programma's is veel aandacht voor zelfmanagement. Enkele voorbeelden van geïmplementeerde interventies zijn leefstijl adviezen, interventies gericht op stoppen met roken en/of meer bewegen en betrokkenheid bij het opstellen van een persoonlijk behandelplan of individueel zorgplan. Na implementatie van het disease management programma zien we dat het percentage rokers over de hele linie gedaald is en chronisch zieke patiënten meer zijn gaan bewegen. Daarnaast zien we dat op langere termijn ook de fysieke kwaliteit van leven is verbeterd. De mentale kwaliteit van leven gaat echter zowel op korte als lange termijn achteruit. De geïmplementeerde interventies richten zich met name op leefstijl en de fysieke kwaliteit van leven van patiënten. In de toekomst is meer aandacht nodig voor de mentale aspecten van het leven met een chronische aandoening.

Summary

In total, 22 regional practice projects were developed, followed and evaluated within the framework of the ZonMw programme '*Disease Management Chronische Ziekten*' (Evaluating disease-management programmes in chronic care; DMCZ). The duration of these ZonMw practice projects was approximately three years. During this period the projects were systematically monitored on a number of process- and effect outcomes and cost-effectiveness. Disease-management programmes based on Ed Wagner's chronic care model are expected to enhance quality of chronic care delivery. Insight into the short and long-term effects of implementation of this type of programme for different chronic conditions is still scarce, however. Questionnaires were sent in the years 2010, 2011 and 2012 to all patients and professionals involved in these 22 disease-management projects in the Netherlands. This survey shows that quality of chronic care delivery substantially improved over these years. Moreover, in the short term (after one year) patients exercised more and the number of smokers had decreased. On the other hand, physical and mental quality of life had worsened after one year. After two years the tide had turned; the disease-management programmes appeared to have improved not only the patients' health behaviour (exercise, smoking habit) but also their physical quality of life. Furthermore, the data registered by the general practitioners' practices showed that clinical outcomes had improved. Mental quality of life, however, decreased over time. With regard to cost-effectiveness, there are no indications of care substitution from hospital care to the primary care sector. The disease-management programmes overall were not yet cost-effective after two years. Still, the individual programmes showed different cost-effectiveness outcomes.

Important factors for the development and implementation of the projects were the extent to which the required system changes had been anticipated and the level of flexibility to respond to the needs of health professionals and patients during the process. Improved communication and coordination between professionals appeared to be the major predictors for successful implementation of the practice projects. Communication is effective when it is frequent, timely, accurate and aimed at solving problems. Mutual respect, shared goals and shared knowledge are relational aspects essential for effective coordination. Care delivery to chronically ill patients requires optimal coordination between different types of professionals: general practitioners, primary care practice assistant, dietician, physiotherapist, occupational therapist, medical specialist, et cetera. Only when professionals of different backgrounds work well together they will be able to offer proper support to the chronically ill and thus improve quality of care.

Not unimportantly, the question was raised whether the disease management programmes would be sustained in practice after ZonMw funding was stopped. A selected number of programmes were therefore monitored one year longer, for the duration of 2013. The answer indeed appeared to be affirmative: improvements in quality of care, patients' health behaviour and physical quality of life were sustained, although improvement in mental quality of life had not yet been achieved.

The results also show that quality improvements both during the first year and the second year after implementation predict successful sustainment of the disease management programmes, as perceived by the health professionals involved.

Likewise, results from the survey show that the patients on average perceive improved quality of care delivery. Still, professionals are aware of improvements in chronic care delivery at an earlier

stage than are the patients; for example through complying with protocols, using a (Chain) ICT-system and establishing collaborations with other professionals. This perception appears to predict a more positive patient perception of quality of care delivery one year later. This finding emphasizes the importance of improvement in quality of care even if this has not yet had an impact on patients.

Of great importance in the care process is the role of the patients themselves. This is why the disease management programmes place a focus on self-management. Interventions aimed at self-management include lifestyle counselling, smoking cessation and exercise programmes and active involvement in drawing up a personal treatment plan. The effect was a lower percentage of smokers and more intense exercise after implementation of the disease management programme. In addition, patients' physical quality of life improved on the longer term. On the other hand, mental quality of life declined both on the short term and the long term. Seeing that the self-management interventions notably were targeted to life style and physical quality of life, it would be worthwhile also to pay more attention in the future to the mental quality of life aspects of having to live with a chronic condition.

Key lessons

- **Dutch disease management programmes improved the quality of chronic care delivery over time**

- **Disease management programmes appear to improve physical activity and reduce the percentage of current smokers among chronically ill patients over time**

- **(Changes in) health behaviour are important for the physical quality of life of chronically ill patients**

- **Preparation and flexibility throughout the disease management programme can lead to better quality of chronic care**

- **Rich interaction among professionals conducting disease management leads to better quality of chronic care delivery**

- **Care quality and changes therein predict more positive experiences of patients**

- **Short and long term improvements in quality of chronic care delivery in the Netherlands leads to programme sustainability**

- **There is a wide variation in the development and implementation costs of disease management programmes. This is driven primarily by the duration of the development phase and the number of professionals involved. Economies of scale are very important because the development and implementation costs per patient reduce when the number of enrolled patients increases**

- **There was no statistically significant change in costs of healthcare utilisation or the total societal costs during the first year of follow-up. On average, the mean healthcare and total costs per patient were lower during the second year as compared to the year before the start of the project, but not significantly**

- **There were no indications of direct substitution of hospital care by primary care**

Chapter 1: Introduction

The combination of rapid aging of populations and greater longevity results in the increased prevalence of chronic diseases (Wagner et al. 2001), which, in turn, leads to deficiencies in the organization and quality of care delivery. Care for chronically ill patients is characterized by under-diagnosis, under-treatment and failure to use primary and secondary preventive measures (Roland et al. 2005). Although many advances have been made in the treatment available to chronically ill patients, these patients do not always receive optimal care (Nolte & McKee, 2008; Norris et al., 2003; Renders et al., 2001). Healthcare delivery often focuses on acute problems and rapid short-term solutions, without effective treatment or the active involvement of chronically ill patients (Lenfant 2003). Historically, healthcare delivery did not focus on enhancing patients' self-management abilities because the full clinical course of acute diseases often encompasses a period of days or a few weeks (Wagner et al., 2001). Care delivery to chronically ill patients remains acute-driven in most healthcare practices and system design has been identified as a fundamental barrier to quality improvement.

The rapid growth in the number of individuals with chronic conditions and the failure of healthcare systems and organizations to meet the needs of these individuals have made disease management a priority in healthcare policymaking in many countries. Key policy reforms that enabled disease management in the Netherlands are: the Health Insurance Act (2006), which created a mandatory insurance system introducing the possibility of selective contracting with collectives to target care delivery to those with chronic conditions; the Social Support Act (2007), which introduced provisions to enable chronically ill and/or disabled people to live independently and participate in society; the Act for Allowances for the Chronically Ill and Handicapped Persons (2009), which entitled chronically ill and disabled persons to receive a fixed allowance to compensate for excessive healthcare expenses; and the amendment of the 1993 Individual Healthcare Professions Act, which facilitated the use of nurses in the care of chronically ill and elderly people (Nolte & Hinrichs, 2012).

Another reform was the introduction of a bundled payment system which was piloted in 2007 for diabetes and expanded in 2010 to include COPD and cardiovascular disease management (Tsiachristas et al., 2011). The aim of these payment reforms was to improve coordination between providers, promote the use of disease management programmes, strengthen adherence to medical guidelines and increase quality of patient records. Under the new payment scheme chronic care is coordinated by groups of providers (called care groups) that implement disease management programmes organised in integrated centres in primary care or in groups of cooperating general practices, paramedical care givers and/or hospitals. Insurers negotiated with care groups a predefined fee (bundled payment) that covered all care needed by a patient with a particular chronic disease for a year (excluding inpatient care, medication, medical devices and diagnostics). Then care groups negotiate with and subcontract individual care providers for the care delivery. Negotiations generate significant price variations between care groups for a particular group of patients i.e. different prices for different diabetes disease management programmes, serving to promote competition-induced quality improvements, on the basis of, but not limited to, performance measures, which are described in national care standards. Insurers are free to choose whether they contract care groups based on the bundled payment system or instead provide care groups only with an additional payment for the organisation, coordination and transparency of care,

while continuing to reimburse individual providers on a fee-for-service basis (Tsiachristas et al., 2013).

Furthermore, in 2008 the government tried to create a nationwide push to improve the quality of care for chronically ill patients through a programmatic approach to chronic illness care (Ministry of Health, Welfare and Sport). This also led to the ZonMw programme Disease management Chronic Diseases ("Chronische Ziekten") which was launched in 2008 (http://www.zonmw.nl/nl/programmas/programma-detail/diseasemanagement-chronische-ziekten/algemeen/). This programme aimed to slow the increase in chronic diseases, to prevent or delay complications and co morbidity and to promote patients' quality of life and control over their own health. 'Disease management' is a broad programmatic approach existing of diagnostics, treatment and counselling, including prevention, early detection and self-management. This integrated approach, laid down in multidisciplinary standards of care, is organised around the patient and his or her environment. The patient is assigned an active director's role, in which continual dialogue between patient and caregivers is central. Disease management requires appropriate management and financing structures. To meet these requirements, Ed Wagner's chronic care model (Wagner et al. 2001) was a starting point for all the 22 participating practice projects.

The aim of this study is to evaluate these projects by capturing them in a common conceptual framework and by using similar structure, process and outcome measures, study the ways in which disease management programmes are enacted in practice and study the cost-effectiveness of disease management programmes.

The study aims to lead to both a better understanding of the mechanisms of disease management (components) and ads to our knowledge about the feasibility and cost-effectiveness of a disease-management approach to improve healthcare. The guiding research questions are as follows:

1) Can we develop and apply a common framework to describe and compare the components of each disease management programme and each patient population?

2) What are the effects of disease management interventions on the primary outcomes at the patient, professional and organisational level?

3) What interventions are actually performed within the context of the 'disease management in chronic diseases' programme?

4) What are the total costs (including implementation costs and all downstream healthcare costs) associated with the interventions and how are they financed and reimbursed?

5) How do these costs relate to the effects described under (2)?

6) What are crucial success and failure factors that influence the effect of disease-management interventions, what determines sustainability and how is this spread to other settings?

Chapter 2 describes the chronic care model. All disease management programmes redesigned their existing practices and began to develop and implement new interventions consistent with (parts of) the chronic care model. In Chapter 3 we present the methods used to answer the guiding research

questions. In Chapter 4 we give a full overview of interventions used within the 22 disease management programmes and show how disease management programmes are actually developed in practice using thick descriptions of three disease management programmes. These thick descriptions explain how different views about self-management and disease management, different histories of the practices and different experiences with interventions led to the development and implementation of different types of disease management programmes. Improvements in quality of chronic care delivery according to the chronic care model are described in Chapter 5. Chapter 6 presents effectiveness of disease management programmes on patient outcomes. We report short-term effectiveness (baseline (2010) *versus* T1 (2011)), long-term effectiveness (baseline (2010) *versus* T2 (2012)) and sustainability (baseline (2010) *versus* T3 (2013)) and clinical outcomes. Costs of disease management programmes are presented in Chapter 7 and cost-utilities in Chapter 8. In Chapter 9 we explain success factors of disease management programmes (e.g. preparation, flexibility, interaction among professionals, sustainability, spread to other settings and co morbidity). Final discussion and conclusions can be found in Chapter 10, where we will answer the six research questions described above.

Chapter 2: The chronic care model

The delivery of effective and high-quality chronic care requires comprehensive system changes that entail more than simply implementing interventions or adding new features to the existing acute-focused system. Evidence strongly suggests that multi component interventions are required to change the processes and outcomes of chronic care delivery (Cramm, Rutten-Van Mölken and Nieboer 2012; Nolte and McKee 2008; Wagner, Austin and Von Korff 1996a, 1996b). The chronic care model aims to transform the system of chronic disease care delivery from acute and reactive to proactive, planned and population based (Wagner et al. 2001; Coleman et al. 2009; Norris et al. 2003; Tsai et al. 2005; Wagner, Austin and Von Korff 1996a, 1996b). This multidimensional framework was developed as a foundation for the redesign of care practices and seeks to improve the quality of chronic care delivery through enhanced productive interactions between informed, activated patients and proactive care teams (Bowen et al. 2010). Wagner and colleagues (2001) designed the chronic care model based on evidence from a review of interventions to improve quality of chronic care delivery (Wagner et al. 1996a). The evaluations and findings from a Cochrane Collaboration review confirmed that interventions based on the chronic care model led to improved quality of chronic care and patient outcomes (Renders et al. 2001). Accumulated evidence in more recently conducted meta-analyses support the notion that the chronic care model is an effective integrated framework to guide practice redesign to improve patient care and health outcomes of chronically ill patients (Coleman et al. 2009; Tsai et al. 2005).
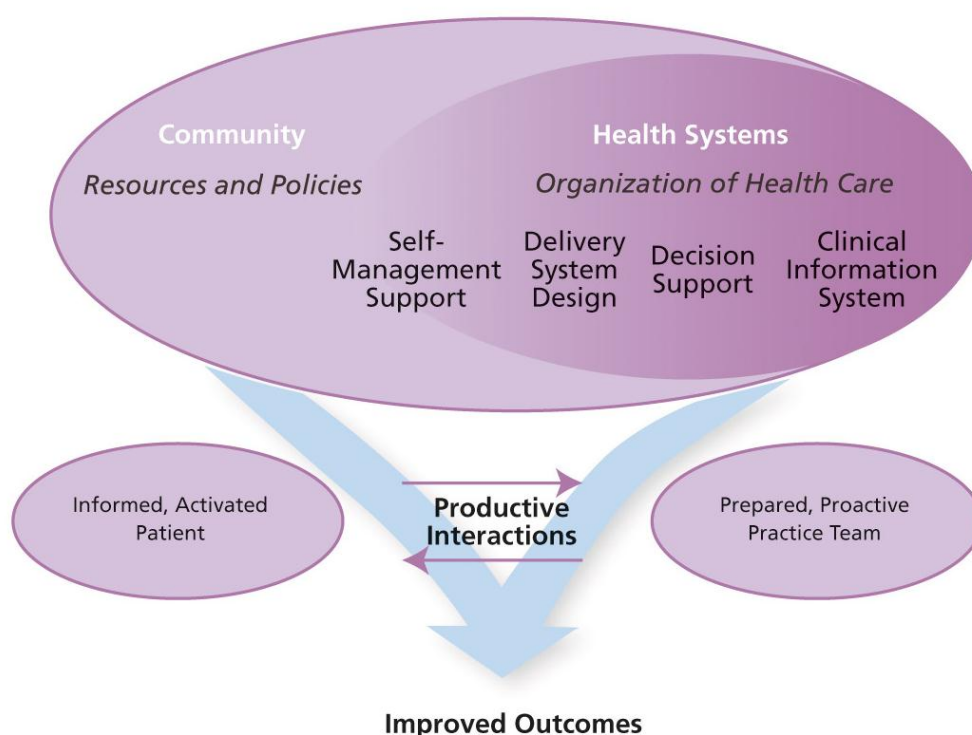
Wagner's Chronic Care Model

The chronic care model was designed to improve the quality of integrated care over time. Well-functioning teams of professionals with different backgrounds apply the principles of this model in their daily practices. The model consists of six interrelated components, which together determine the quality of chronic care delivery. General practitioners apply the principles of disease management by addressing chronically ill patients' self-management abilities through education, lifestyle programmes and training in skills, such as self-efficacy (1). Furthermore, they redesign the care process (2), make use of decision support resources, such as standards of care and clinical guidelines (3) and implement information systems to improve communication and mutual coordination among professionals and support communication between patients and professionals. In the end, this approach leads to better decision making, with feedback based on available information, as well as better monitoring of the effectiveness of care for individual patients (4). These four dimensions of chronic care– self-management support, decision support, organisation of care and clinical information systems – are embedded in the wider context of the healthcare system, which positively or negatively influences the improvement of chronic care (5) and the surrounding community, which can be more or less supportive (6).

Chapter 3: Methods

3.1 Setting

Our study was performed in the context of a national programme on 'disease management of chronic diseases'. Requirements of the national programme were that the practices had to have some experience with the delivery of integrated chronic care and were equipped to implement multiple systems needed for the delivery of sufficient chronic care, which resulted in the inclusion of 22 disease management programmes (out of 38 applications to participate in the national programme). These disease management programmes targeted several patient populations: cardiovascular diseases (CVD), chronic obstructive pulmonary disease (COPD), diabetes type II, heart failure, stroke, patients with multiple of these morbidities, depression, psychotic diseases and eating disorders.

To describe the disease management programmes, we used a concurrent nested mixed-methods approach (Creswell, 2003). We collected baseline quantitative data on the patient and organisational levels during the early implementation stage of the programmes. A detailed description of the methods we employed in our research can be found in our study protocol (Lemmens et al. 2011).

The study was approved by the ethics committee of the Erasmus University Medical Centre of Rotterdam in September 2009. Data were collected anonymously and treated confidentially to protect sensitive patient information.

3.2 Quantitative study - professionals

In 2010, most disease management programmes had finished implementing interventions and training professionals and had started to enrol patients. At this time (T0), we sent a questionnaire to all 393 professionals (nurses, medical doctors, practice nurses, GPs, dieticians, physical therapists, etc) participating in the 22 disease management programmes. A total of 218 respondents completed the questionnaire (55% response rate). One year later (in 2011; T1), we sent a questionnaire to 433 professionals participating in the disease management programmes at that time. A total of 300 respondents completed the questionnaire (68% response rate). Two years later (in 2012; T2), we sent a questionnaire to 421 participating professionals, which was completed by 265 respondents (63% response rate). A total of 106 respondents (still representing the 22 disease management programmes) completed the questionnaires at all measurement points (T0, T1 and T2). In addition, we sent questionnaires to the professionals working within the 9 disease management programmes we followed after the ZonMw funding had ended in 2013. We received questionnaires from 73 respondents (out of 189; response rate of 39%). Questionnaires were distributed to potential respondents through a contact person at each participating organisation (through internal mailboxes or personal delivery at team meetings) or by direct mailing. A few weeks later, the same procedure was used to send a reminder to non-respondents. No incentive in the form of money or gifts was offered.

Measurements professionals

We used the Assessment of Chronic Illness Care Short version (ACIC-S) to investigate professionals' assessment of chronic care delivery (Cramm et al. 2011; Cramm and Nieboer 2012a; Cramm and

Nieboer 2012b; Cramm and Nieboer 2013a; Cramm and Nieboer 2013b). The ACIC-S consists of 21 items covering the six areas of the chronic care model: healthcare organisation (n = 3), community linkages (n = 3), self-management support (n = 3), delivery system design (n = 3), decision support (n = 3) and clinical information systems (n = 3). Additional items integrate the six components, such as by linking patients' self-management goals to information systems (n = 3). Responses to Assessment of Chronic Illness Care Short version items (e.g., "evidence-based guidelines are available and supported by provider education") fall within four descriptive levels of implementation ranging from "little or none" to "fully implemented intervention." Within each of the four levels, respondents are asked to choose the degree to which that description applied. The result is a 0–11 scale, with categories defined as 0–2 (little or no support for chronic illness care), 3–5 (basic or intermediate support), 6–8 (advanced support) and 9–11 (optimal or comprehensive integrated care for chronic illness). Subscale scores for the areas of the chronic care model are derived by calculating the average score for all items in that subsection of items. Mean subscale scores were calculated if at least 2 out of 3 items were available. Total scale scores were calculated by average scores on the subsections (when at least 4 out of 7 subsections were available).

Relational coordination - that is the quality of coordination and communication between professionals - is an important predictor of a team's ability to achieve its performance objectives. Relational coordination was measured using seven survey questions: four questions about communication (frequency, timeliness, accuracy, problem solving) and three questions about relationships (shared goals, shared knowledge, mutual respect). Relational coordination was measured on a four-point scale, with higher scores indicating better quality of interactions between professionals.

Sustainability of new practices was assessed with eight items from the routinization instrument (Short Version) as developed by Slaghuis et al. (2011). These eight items concern the two subscales routinization I and II, which are most applicable to assess if professionals changed their old working habits and integrated the new working method in their routine practices. Example of items are: 'the new practice is regarded as the standard way to work', 'the new work practice is easy to describe', 'all colleagues involved in the new work practice are knowledgeable about it' and 'the work practice has replaced the old routine once and for all'. Responses are structured by a five-point scale (ranging from '1: I don't agree at all' to '5: I agree very much'), with higher scores indicating greater sustainability.

Spread of the new practices was assessed with five items from the measurement instrument for spread of quality improvement in healthcare (Slaghuis et al. 2013). Slaghuis and colleagues (2013) showed that the psychometric properties of the measurement instrument are good and warrant application of the instrument in the evaluation of improvement projects, such as disease management programmes aiming to improve quality of chronic care. These five items concern the extent to which knowledge related to the disease management programme is available and being used in other settings.

Analyses professionals

We used descriptive statistics to describe the study population. Two-tailed, paired *t*-tests were used to investigate improvements in quality of chronic care delivery over time. We investigated first-year

changes in the quality of chronic care delivery (T0: 2010 versus T1: 2011) and second-year changes in the quality of chronic care delivery (T1: 2011 versus T2: 2012). In addition, we investigated if disease management programmes were able to sustain their improvements in quality of chronic care in 2013 after funding of ZonMw ended. We employed multilevel random-effects models to investigate relationships over time.

3.3 Quantitative study - patients

In 2010 (T0), we sent a questionnaire to all 5957 patients enrolled in the 22 disease management programmes. A total of 2979 respondents completed the questionnaire (50% response rate). One year later (in 2011: T1), we sent a questionnaire to 5258 patients still enrolled in the disease management programmes at that time. A total of 2487 respondents completed the questionnaire (47% response rate). Two years later (in 2012: T2), we sent a questionnaire to 4646 enrolled patients, which was completed by 1943 respondents (42% response rate). In addition, we sent questionnaires to the patients working within the 8 disease management programmes we followed after the ZonMw funding had ended in 2013. Due to a different timing of distributing patient questionnaires we were not able to send T3 questionnaire to those at Ursula. We received questionnaires from 787 respondents (out of a potential 2077; response rate of 38%). See Appendix Chapter 3 (1) for a full overview of response rates within each disease management programmes at all measurement points.

Measurements patient outcomes

Patients' physical and mental quality of life was assessed using the physical and mental component of the Short Form 36 Health Survey (Ware & Sherbourne 1992; Aaronson et al. 1998). Selected items and weights derived from the general Dutch population were then used to score the physical quality of life component (Ten Klooster et al. 2013), with higher scores indicating more positive ratings.

Physical activity was assessed by asking respondents how many days per week they were physically active (e.g., sport activities, exercise, housecleaning, work in the garden) for at least 30 minutes. Smoking was assessed with a 'yes' or 'no' question.

We assessed background characteristics such as age, gender, marital status and education. Patients' educational levels were assessed on six levels ranging from 1 [no school or primary education (≤7 years)] to 6 [university degree (≥18 years)]. We dichotomised this item into low (no school or primary education) or high (more than primary education) educational level.

Measurements cost-effectiveness

To determine cost-effectiveness the 3-level EQ-5D questionnaire to assess generic quality of life was used, which includes the domains: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. EQ-5D utilities were calculated using the Dutch value set (Lamers et al., 2006). The utilities were used to calculate Quality adjusted life years (QALYs) using the area under the curve method.

The development cost and implementation costs of the disease management programmes were systematically collected using an Excel template developed based on the CostIt instrument of the

World Health Organisation (WHO) (Johns et al., 2003). This template was completed during face-to-face interviews with disease management programme managers. The development costs included all costs made during the preparation phase of disease management programmes, e.g. labour costs for brainstorming sessions, training costs and ICT support costs. The implementation costs included costs of multidisciplinary team meetings, coordination between care-givers, monitoring and feedback. Annual implementation costs were estimated for the two years after the disease management programme implementation.

During these interviews managers stated the presence of additional financing and payment to cover the specific elements of integrated care.

Besides the development and implementation costs, we also collected data about the duration of the development phase (in months), the number of disease management programme participants, the total Full-Time Equivalents (FTEs) available to the organisation providing a disease management programme and the FTEs dedicated to develop and implement the disease management programme. The costs of development were amortised in 5 years assuming this period as the life span of a disease management programme since after this period changes in guidelines and governmental policies would probably affect the initial form of a disease management programme. The development and implementation costs per patient were consequently calculated by adding one fifth of the development costs to the annual implementation costs and dividing it by the number of disease management programme participants.

The costs of healthcare utilisation were based on a questionnaire asking about the number of caregiver contacts (GP, nurse practitioner, nurse, dietician, physiotherapist, podiatrist, lifestyle coach, medical specialists in outpatient clinics etc.), hospital admissions and admission days and medication use. The recall period for these questions was 3 months and we asked for all healthcare utilisation, whether or not it was related to the disease targeted in the disease management programme. In addition to these costs, the travel costs of patients were calculated, using their self-reported distance to a healthcare provider. Finally, the costs of productivity loss due to illness were calculated, using the friction cost approach (Koopmanschap et al., 1995), based on questions about absence from paid employment due to illness. Standard unit costs as reported by (Tan et al., 2012) were applied. All costs were inflated to 2012 levels and reported on an annual basis per patient.

Analyses patients

We used descriptive statistics to describe the study population. Two-tailed, paired *t*-tests, Wilcoxon paired test or McNemar chi-squared tests were used to investigate improvements in patients' health behaviour and physical and mental quality of life over time. We report short-term effectiveness (baseline (2010) *versus* T1 (2011)) and long-term effectiveness (baseline (2010) *versus* T2 (2012)). In addition, we investigated if disease management programmes were able to sustain their effects after funding of ZonMw ended (baseline (2010) *versus* T3 (2013)). We employed multilevel models to investigate relationships over time.

In each disease category, we identified the disease management programme that was most effective and least effective in improving the level of integrated chronic care as measured by the ACIC-S (Cramm et al. 2011). In each disease category, we identified the disease management programme that was most effective and least effective in improving the patients' generic health-related quality

of life as measured by the EQ-5D. In this manner we identified 5 pairs of disease management programmes (i.e. for primary CV prevention, secondary CV prevention, both types of CV prevention, COPD and DM). For each of the 5 pairs, we calculated the cost-utility of the most effective versus the least effective disease management programme in terms of incremental costs per QALY gained. These calculations were performed from two perspectives, i.e. the healthcare perspective (including the costs of development, implementation and healthcare utilisation) and the societal perspective (adding the costs borne by patient for travelling to receive care and the costs of productivity loss due to absence from paid work to the costs from the healthcare perspective). We also performed the cost-utility analyses excluding the development and implementation costs as sensitivity analysis.

We used inverse probability weighting to balance the two comparators in each pair with respect to age, gender, education, presence of multi-morbidity, marital status and EQ-5D at baseline. Inverse probability weighting was chosen because it is the preferred propensity score matching technique for small samples (Stuart, 2010). We performed bootstrapping to generate 5,000 samples from the original sample. For each bootstrapped sample we estimated a generalised linear model for each outcome variable (i.e. QALYs or costs) using the inverse probability weights to adjust the model coefficients for the propensity score of each observation as well as age, gender, education level, multi-morbidity and marital status. In this manner, 5,000 predicted incremental costs and 5,000 predicted incremental QALYs were generated. Each of the 5,000 Incremental Cost-Effectiveness Ratios (ICERs) was calculated as the mean of the predicted incremental costs divided by the mean of the incremental QALYs. These predicted ICERs were then plotted on a cost-effectiveness (CE) plane to show the uncertainty in the ICER. The CUA was also performed excluding the development and implementation costs in order to investigate how sensitive the estimated ICERs are to these costs.

3.4 Qualitative study

Baseline interviews were conducted in all disease management programmes (n=22) within three months of selection for funding through the national programme. The baseline interviews served multiple purposes: to understand the organisation, roles and responsibilities of the project team, to learn about the goals of the project from the project leader's point of view and to gain an overview of all projects so that five programmes could be selected as case study site for further in-depth qualitative research. Three additional rounds of interviews with project leaders were also conducted. Additional interviews (total: 3) were conducted with managers from Vilans, Picasso and ZonMw.

Case studies

As part of the larger evaluation of the 22 disease management programmes, five case study sites were chosen for in-depth research. The selection criteria were: spread over regions, maturity of the projects, intended patient groups anticipated change due to new forms of collaboration between care professionals (including between primary and secondary care) and different kinds of targeted interventions.

Thick descriptions

Five sites were chosen for in-depth research to understand the processes taking place in the practices. In this report three disease management programmes (Ursula, Zeist and Radboud) are

described in depth to understand how disease management programmes are enacted in practice, how project leaders and healthcare professionals defined key concepts related to the programmes, such as disease management and self-management and how this led to the implementation of various types of interventions based on the chronic care model. To answer these questions, we used a multi-method qualitative approach for data collection at the sites. These methods include interviews of healthcare professionals and patients, observations, document analysis and online data collection.

In total, 118 interviews were conducted as part of the qualitative research. Twenty-two of the 118 interviews were initial interviews and were conducted by the research project manager and one of the qualitative researchers. These interviews were informational interviews and provided background information on the projects. The content of these interviews informed the selection of the five qualitative cases. Thirty-seven of the 118 interviews were interviews conducted with project leaders and/or managers at practice sites that were not selected for in-depth qualitative study. Fifty-six of the 118 interviews were conducted in the in-depth qualitative cases; see Appendix Chapter 3 (2). Our main research questions, theoretical framework and document analysis formed a basis for interviews in both the in-depth sites and sites not selected for in-depth research; see the sample interview guide (Appendix Chapter 3 (3)). The interviews focused on the disease management programmes, how the medical professional views self-management, their thoughts on how patients will view/currently view self-management, the computerised system for the programmes, their thoughts on how the patient will/do interact with the computerised system and other general disease management strategies. Interviews were recorded and transcribed verbatim. Detailed notes and observations were also taken during the interviews. Interviews with healthcare professionals, IT specialists and project leaders were conducted in Dutch or English and ranged from 30 minutes to 90 minutes.

Seven patient interviews were conducted with patients in the diabetes project (Zeist) and focused on the patients' experiences with diabetes and diabetes treatment. The patient interviews were conducted in Dutch, English and/or German and lasted from 15 to 60 minutes. Three of the patients interviewed were unable to fully conduct an interview due to language mismatch with the interviewer; these interviews nonetheless provide interesting data on the patient experience, especially in regard to language. Further patient interviews were not possible, but information on the patient experience was collected through online data collection, observations and asking healthcare professionals and project leaders about the patient experience.

Observations

Observations were conducted at Zeist and at Ursula. At Zeist, one half-day of observations of nurse specialist and nutritionist visits were conducted. One morning of the diabetes education course and one group meeting of healthcare professionals involved in the disease management programme were also observed. At Ursula, two organisational meetings were observed, as well as one information session with area nutritionists. Detailed field notes were taken and worked into the thick descriptions found in the case studies.

Online data collection

Online data collection was conducted on GP Cooperative in Zeist website and on the Proud2Bme site (Ursula). We collected data that was available without a log-in on all sites. On the Zeist site, data was collected about the cooperative and the diabetes program. On the Proud2Bme website, we primarily (though not solely) collected data from the 'experience stories' portion of the website, which offered insight into patient's stories.

Analytic methods

The qualitative data was analysed inductively. Each interview transcription, project plan and document was first read closely to establish general knowledge of the data. Each piece of data was then reread and coded into themes, based on the content. A memo sheet was made for each theme, with references back to the original speaker, document, or webpage. We did not superimpose themes on the data, but rather uncovered and coded themes that occurred naturally in the data. Our chosen method of inductive analysis provided the opportunity to map the themes back to literature on disease management, surveillance and self-management (Creswell, 1994).

Chapter 4: Description of the disease management programmes

The 22 disease management programmes redesigned their existing practices and began to develop and implement new interventions consistent with the chronic care model, which was specifically designed to improve the quality of chronic care delivery over time as healthcare professionals and other program staff more fully incorporated the model's principles into their activities (Cramm and Nieboer 2013a; Cramm and Nieboer 2013b; Cramm et al., 2013; Cramm and Nieboer 2012a; Cramm and Nieboer 2012b; Cramm and Nieboer 2012c; Lemmens et al. 2011; Walter et al. 2012). As self-care is critical for the optimal management of chronic diseases (Cramm and Nieboer 2012d), most programmes included interventions to enhance self-management by educating patients in abilities related to lifestyle, regulatory skills and proactive coping. In addition, the implementation of appropriate care standards, guidelines and protocols were essential parts of the disease management programmes (see overview of interventions used within the 22 disease management programmes on the next page). They were integrated through timely reminders, feedback and other methods that increased their visibility at the time of clinical decision making. The implementation of these guidelines was supported by information and communication technology tools, such as integrated information systems. Furthermore, many forms of organisational change were applied in the disease management programmes, including new collaborations among care providers, efforts to increase the effectiveness of information transfer and appointment scheduling, case management, the use of new types of health professionals, the redefinition of professionals' roles and redistribution of their tasks, planned interaction among professionals and regular follow-up meetings.

Most used interventions (in > 80% of the 22 disease management programmes) were: cooperation with external community partners, treatment and care pathways in out- and inpatient care, promotion of disease specific information, life-style interventions, personal coaching, motivational interviewing, use of care standards / clinical guidelines, training and independence of practise assistants, professional education and training for care providers, automatic measurement of process/outcome indicators, delegation of care from specialist to nurse/care practitioner, meetings of different disciplines for exchanging information and Hospital or Practice Information System.

Less used interventions (in < 20% of the 22 disease management programmes) were: communication platform between stakeholder about patients, health market, support of self-management (via internet, email or sms, e-consultation), reflection meetings, cognitive behavioural therapy, use of care protocols for immigrants, specific plan for immigrant population, joint consultation hours and use of Electronic Patient Records system with Patient Portal. None of the disease management programmes used tele-monitoring. A noticeable difference between somatic and mental disease management programmes is that the mental disease management programmes are more strongly focussed on family participation.

Overview of implemented interventions within the 22 disease management programmes (DMPs)

CCM dimension	Interventions implemented within the 22 DMPs*	Total	Percentage
Organisational support	Integrated financing	9	41%
Organisational support	Specific policies and subsidies for foreign population	6	27%
Organisational support	Sustainable financing agreements with health insurers	11	50%
Community	Communication platform between stakeholder about patients	2	9%
Community	Health market	1	5%
Community	Cooperation with external community partners	18	82%
Community	Multidisciplinary and transmural collaboration	16	73%
Community	Role model in the area	10	45%
Community	Regional collaboration for spread of the DMP	9	41%
Community	Treatment and care pathways in out- and inpatient care	18	82%
Community	Involvement of patient groups and panels in care design	11	50%
Community	Regional training course	16	73%
Community	Family participation	6	27%
Self management	Promotion of disease specific information	18	82%
Self management	Individual care plan	16	73%
Self management	Life-style interventions (e.g. physical activity, diet, smoking)	18	82%
Self management	Support of self-management (e.g. internet, email or sms)	3	14%
Self management	Tele-monitoring	0	0%
Self management	Personal coaching	19	86%
Self management	Motivational interviewing	20	91%
Self management	Informational meetings	7	32%
Self management	Diagnosis and treatment of mental health issues	11	50%
Self management	Reflection meetings	1	5%
Self management	Group sessions for patient and family	6	27%
Self management	Cognitive behavioural therapy	3	14%
Decision Support	Care standards / Clinical guidelines	21	95%
Decision Support	Uniform treatment protocol in out- and inpatient care	10	45%
Decision Support	Training and independence of practise assistants	20	91%
Decision Support	Professional education and training for care providers	21	95%
Decision Support	Automatic measurement of process/outcome indicators	18	82%
Decision Support	Use of care protocols for immigrants	1	5%
Decision Support	Audit and feedback	13	59%
Decision Support	Periodic evaluation of interventions and goal achievement	7	32%
Decision Support	Structural participation in knowledge exchange/best practices	14	64%
Decision Support	Quality of Life questionnaire	10	45%
Decision Support	Evaluation of healthcare via focus-groups with patients	6	27%
Decision Support	Measurement of patient satisfaction	13	59%
Delivery System Design	Delegation of care from specialist to nurse/care practitioner	19	86%
Delivery System Design	Substitution of inpatient with outpatient care	12	55%
Delivery System Design	Systematic follow-up of patients	17	77%
Delivery System Design	One-stop outpatient clinic	5	23%
Delivery System Design	Specific plan for immigrant population	4	18%
Delivery System Design	Meetings of different disciplines for exchanging information	20	91%
Delivery System Design	Monitoring of high-risk patients	13	59%
Delivery System Design	Board of clients	7	32%
Delivery System Design	Periodic discussions between professionals (and patients)	12	55%

Delivery System Design	Expansion of chain care to the secondary care setting	7	32%
Delivery System Design	Joint consultation hours	3	14%
Delivery System Design	Stepped care method	8	36%
ICT	Electronic Patient Records system with Patient Portal	2	9%
ICT	Hospital or Practice Information System	20	91%
ICT	Integrated Chain Information System	10	45%
ICT	Use of ICT for Internal and/or regional benchmarking	16	73%
ICT	Systematic registration by every caregiver	17	77%
ICT	Create a safe environment for data exchange	10	45%
ICT	Exchange of information between different care disciplines	15	68%

CCM=chronic care model

Description of the organizational support interventions

The payment methods of the disease management programmes per disease are presented in Figure 4.1. As this figure shows, the care delivered by 67% of the cardiovascular (risk) disease management programmes (CVR-DMPS) and 50% of the Chronic Obstructive Pulmonary Disease (COPD) disease management programmes was paid based on a "normal" payment (i.e. capitation and fee-for-service). At T1, 22% of the CVR-DMPs and 75% of the COPD-DMPs had bundled payment contracts. The 3 Diabetes Mellitus disease management programme (DM-DMPs) had a bundled payment during the total period of this study. At T2, 22% of the CVR-DMPs and 75% of the COPD-DMPs had bundled payment contracts. The 3 Diabetes Mellitus disease management programme (DM-DMPs) had a bundled payment during the total period of this study.

Figure 4.1. Payment method of disease management programmes
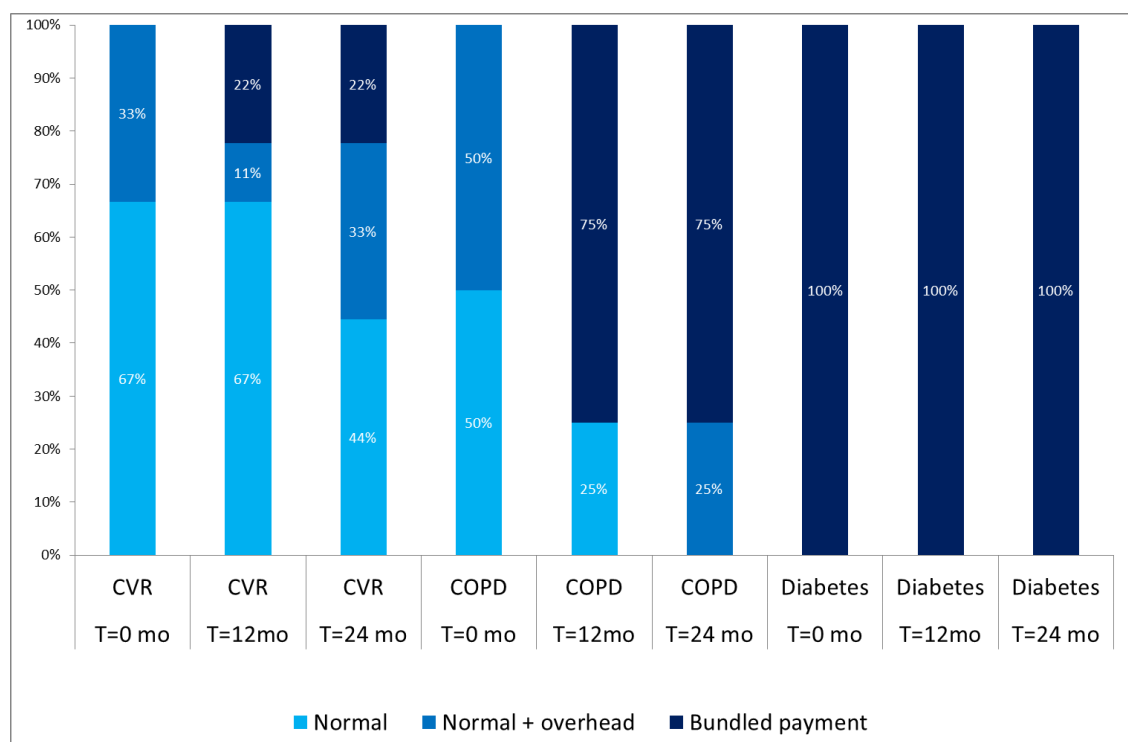
COPD= Chronic Obstructive Pulmonary Disease; DM= Diabetes Mellitus ; CVR=Cardiovascular risk.

4.1 Thick descriptions of three disease management programmes

In this part of the study, we analyse how disease management programmes develop in practice. While all 22 disease management programmes implemented interventions based (in theory) on the chronic care model, they were all different in their approach and in the role that the chronic care model played in the implementation. These thick descriptions show how different views about self-management and disease management led to the development and implementation of different types of disease management programmes. Furthermore, they provide insights into how various disease management programmes can also (re-)shape care delivery, expectations of healthcare professionals and patients and the respective roles of healthcare professionals, patients and project leaders. This chapter then examines the enactment (Mol 2002) of disease management in practice. A deeper understanding of the practice of disease management programmes is useful not only for the academic community, but will also assist project leaders in developing disease management programmes, healthcare professionals in implementing disease management programmes and ultimately, patients who participate in disease management programmes.

Case descriptions

In the following sections, we describe the following disease management programmes: Ursula, Zeist and Radboud. These cases have been selected for description as they illustrate different aspects of the enactment of disease management. The thick descriptions include quotes from project leaders, healthcare professionals and patients as well as the project proposals and websites. This provides an overview of the disease management programmes, with a focus not only on how disease management actually is/was performed in practice but also on how the programmes were understood by the different participants.

4.1.1 Managing eating disorders at Ursula

Centrum Eetstoornissen Ursula is located near the city of Leiden and offers treatment to persons with an eating disorder, such as anorexia nervosa or bulimia nervosa. Different types of treatment are available such as individual and group therapy with psychologists and other mental health professionals and treatment with nutritionists, physicians and nurses. In-patient treatment is available for those with a severe eating disorder, as well as various forms of outpatient treatment.

In its application for funding for their disease management programmes, the centre stated a broad goal, encompassing a diversity of disease management interventions and the methods to attain these goals:

> *The goal of the project, in close cooperation with primary care, is, for all people in South Holland with an eating disorder, to detect, diagnose and offer treatment that fits the nature and severity of their eating disorder and their desires. To this end, we want to offer a wide range of possibilities, some of which still have to be completed, to complement the care chain, which include the completion of the care change, aspects of which are partially developed into the current care of Ursula: self-management over the internet, joining a support group, expert-patient contact, a general periodic 'testing', psychiatric (intensive) home care and regular outpatient treatment provision. In the 2009 annual plan of the centre,*

the implementation of peer counselling and psychiatric (intensive) care is planned. (Grant application)

At Ursula, multiple smaller interventions fit under the umbrella of disease management. These include a website to support and encourage (mostly) young women with eating disorders or eating problems, an online eating disorder assessment and support tool, a home nurse program and an expert patient/support group program based in the treatment centre. Other projects have included a respite house, which is unable to go forward and a community education and outreach program in Zoetermeer.

During the course of the disease management project, Ursula underwent a significant reorganisation of care delivery. This reorganisation occurred over a period of many months. Through mediated meetings, care professionals honed notions of what it meant to deliver care to young women with eating disorders. In the reorganisation of care, the disease management programmes have been integrated into the new care delivery system, making it somewhat difficult to separate out which programmes are disease management programmes. With this in mind, we have described the programmes that fit the original goals of the grant application and were mentioned by the project director in the initial interviews as being part of the disease management project. We have also included the future efforts in Zoetermeer, as these efforts align with disease management principles of community outreach.

It should be noted, however, that in many ways, the disease management programme at Ursula is a unique case and was chosen as a critical case for the qualitative research because of the uniqueness of the program offered there. The programmes at Ursula, unlike more classical disease management programmes, focus on prevention and the early management of eating disorder behaviour, in the hopes of preventing chronic eating disorders. Analysing this case enabled better understanding of how disease management programmes work with non-traditional populations and program focus.

Information systems: website Proud2Bme

One of the key ways that care has been reorganised is through the offering of care online through the Proud2Bme website. Proud2Bme was started by Eric van Furth and Scarlett Hemkes in 2009 as an alternative to pro-anorexia websites. The site has an active chat forum, regular group discussions with dieticians, psychologists and other eating disorder treatment specialists from Ursula, a hosting space for blogs, stories and a webshop. The website also contains a documentary (*Mij Niet Gezien*) produced by the team at Ursula about the hidden nature of eating disorders. The website is an effort to support young women with eating disorders or eating problems, to work with young women on managing any problems with eating that they may have and to connect young women with medical professionals for future (both online and offline) treatment of their illness.

Between 7.000 and 10.000 people (assumed to be young women, as the site targets young women and their families) visit the site daily. One of the founders of the site hopes to grow this aspect of Proud2Bme in the future through the development of a smartphone app and through offering more tools on the site, based on how the young women use the site:

> *And that's a logical place to start, but if I look at what our girls on [the site] do is that they sort of take some here, take some there. Why not try to provide them with what I would call*

more self-management tools, but sort of what you could also construe as smaller, individualised therapy modules or intervention or whatever… Just offer a food diary or just offer … a cognitive tool in which you can analyse your thoughts and restructure… Sort of take traditional treatment but sort of cut it up into smaller components, offer those as self-management tools. (Interview 2 with project leader, eating disorder project)

Through online treatment, the roles of users/patients and healthcare providers have changed. Users/patients can seek out what they need on the site, including the advice of other users. Professionals are able to tailor care with and to the user's needs in a different way than before, with new opportunities for asynchronous care, for user-led tailoring and for adapting treatment and tools.

The young women see the site as playing a role in their treatment and recovery through the tools available and the support provided by the Proud staff and the other users. The young women wrote of how the others on the site influenced them, helping them gain control of their eating disorders.

The fact that there are so many girls and boys on Proud2Bme that fight to get better made me realise that I can also do it and more than that, I want to. I´m now stronger than before. I have control back, the real control. When I look in the mirror, I see myself as I am again. I have a handle on myself again. (Story 10)

This support from the staff and other users came in the form of comments and of shared stories of similar experiences. The site serves as a literal location of treatment, even if the treatment comes in the form of support from other users.

Proud2Bme creates a new type of patient: the online only patient. As there are no requirements for those visiting the site, the young women who visit the site may only be receiving treatment, support and education about their eating disorder from the healthcare professionals and other users of the site. Not only has the patient role changed, but the clinician role and the delivery of care have also changed. Healthcare professionals are now online educators and supporters for the young women who visit the site; just as patients may be online only patients, healthcare professionals may be online only healthcare professionals for those young women.

And that is why ehealth is so important to us. You are immediately in someone's living room and that is why there is less of a barrier for him/herself. (Interview 1 with second project manager, eating disorder project)

Care delivery is done at a distance in non-clinical spaces, entering the young women's living rooms from their own home (as most of the chats are offered in the evening). In this way, we can see that treatment for eating disorders as part of disease management programmes can be located online through the therapists' chats, comments from other users, in the hosting on a server and through the internet browsing of the young women. The project leaders at Ursula are expanding online treatment beyond the disease management programme and the original Dutch context; in 2012, Ursula contracted with the National Eating Disorders Association in the United States to create an English language version of Proud2Bme for young women in the United States.

Information systems: Email support through Featback

Featback is another of the projects at Ursula under the disease management umbrella. It is an online assessment and self-monitoring tool, based on the German program Essprit, which was developed at the University of Heidelberg. Through Featback, those who are worried that they may have an eating disorder can assess their risk through an online self-assessment and, based on their profile, receive emails supporting them during their management and recovery of their eating disorder.

> *Of course, I hope that many people do join and that people experience it as support… and that it will achieve our goals. That there is more awareness so that people can quickly recognise and acknowledge [eating problems] and they, as a result, seek out help faster, whether it is self-help or something low barrier or treatment. And if they want treatment, the steps to getting treatment are reduced. That's really one of the biggest goals.* (Interview 2 with Featback project manager)

To use Featback, the user needed only sign up once to receive messages for a longer period of time, while the clinician created the messages before the implementation of the program. Both the user and clinician are separated during the care delivery process, which takes place wherever the client checks their email. Treatment, then, is located in the in-box.

Featback shows a further change in the spaces of care through online efforts at self-management and reducing the barriers to care. Unlike the Proud2Bme site, users of Featback do not need to log onto the site to receive encouragement, tips on how to manage their eating problems, or advice; the email comes to them daily, focused on their stated needs.

> *Okay, yeah. A bit like You go, Girl! Kind of things. So it's longer, it's more practical, there's more variation, so I tried to make Featback more different for everyone something else because something works for one person but doesn't work for someone else.* (Interview 1 with Featback project manager)

As care delivery is at a distance, the focus has been on using practical tips and affirming language in the messages, which are delivered daily. As the messages are tailored to their stated needs and are received in a passive manner, the young women who have chosen to use Featback have selected a method that can be easily integrated into the everyday activity of checking email. The patient may be an online only patient, while the clinician role is that of advice-giver and impersonal coach.

Featback website (3 July 2013)

Clinician-based efforts: Support

Further components of the disease management programme at the centre are the expert patient support and home nurse programmes. These are more traditional forms of real-time, face-to face care.

The expert patient support comes in multiple forms, whether from an in-person support group with an expert patient and a clinician leading, a chat with a person in recovery from an eating disorder to learn what treatment is like, or an email from a person in recovery to someone thinking about treatment, facilitated by the expert patient support manager.

> *Now that is the start group, which is led by a sociotherapist and there will soon be two expert-patients to offer support to clients from a different perspective, to help them really get ready for therapy a bit because it really requires quite a bit from you to really go for your healing and to want to get rid of your eating disorder..* (Interview 2 with the first expert patient support manager)

The support groups with a person in recovery attending are now a regular component of treatment for clients and families at the centre.

The young women acknowledge their new roles in directing their own care, as seen in the stories about treatment at Ursula which have been posted on the Proud2Bme website.

> *The contact with the therapists is quite good. You can just call them by their first names and they do everything cozily. They think well with you on how to do something!* (Ursula website: Experiences in Care)

The young woman who wrote about treatment saw healthcare professionals as thinking <u>with</u> them, rather than thinking <u>for</u> them. This co-production of care can be seen in the interviews with project leaders and healthcare professionals.

However, as other stories on the site show, not all patients at Ursula saw themselves as ready for such a changed role, even after treatment has begun.

> *I went through 2 months of 4 days a week part time care at X. But I didn't have much motivation, primarily since you could easily smuggle food out in your pockets and you could also just spit out your food after dinner. This wasn't right; I realised that you had to be motivated to go to X and I wasn't quite ready. So I stopped therapy at X and kept following my eating list. It wasn't a lot, so I could do it pretty easily.* (Story 8)

The young women who sought treatment at the eating disorder centre saw motivation as a needed component of treatment. Treatment, as it is located in multiple physical and non-physical spaces, is larger than attending therapy sessions. By stopping therapy, the young woman has tailored the available care options to her needs but continues to use her eating list, a self-management tool provided by the centre that helps young women monitor and control their eating.

Other face-to-face treatment programmes include a home nurse program, in which a nurse comes to the client's home or hospital. The clients seen include adults and teenagers with a chronic eating

disorder or clients who have been released from another sort of treatment but need additional support. One of the goals of the home nurse program is to create closer connections with the community and offer more intensive support to the young women and their families in the home, a less intensive treatment environment than the hospital or full-day care. The nurse can visit for meals or for chats with parents and also works to coordinate the multiple types of care that the young women may receive.

> *One of my patients is now in the hospital due to underweight. This is primarily a somatic indication…Three times in the week, I sit with her for one of her meals.* (Interview with nurse)

Though not an official education session, the nurse remains a self-management educator as she supports and trains the patient how to eat. The nurse also communicates with and coordinates care between multiple providers, the client, their families and their communities. Much like the care provided by Proud2Bme and Featback, care is located at home, but in this case, is provided by face-to-face interaction with a clinician.

Community outreach

Though both the website and the email program reach out to the community, a further program is a dedicated community outreach program aimed at educating healthcare professionals, teachers, youth care workers and other civil servants about the signs of an eating disorder and how to proceed with a young person suspected of having an eating disorder. Through the community outreach project, the eating disorder treatment centre is striving to reduce the need for more intensive, more expensive treatment by reaching out to young women with an eating disorder/problem while the problem is acute, rather than chronic.

> *So I think that in the long run, if we can really manage the detection and provide the community with the right tools that I really hope that we will be able to decrease the individuals creating an eating disorder and ever needing treatment. And those who do, we have no way to predict of who will respond to the other interventions, if they don't we will provide adequate outpatient treatment.* (Interview 3 with project director)

The community outreach program, currently underway in Zoetermeer, offers a small informational folder for healthcare professionals on how to help young women with a suspected eating disorder and meets with professionals to go over the options available at Ursula. By providing information and treatment strategies, the staff at Ursula hopes to transform roles of other healthcare professionals, youth care workers, teachers and others who work with youth to educate about eating disorders, active in eating disorder outreach and prepared to offer (minor) treatment to those with a disorder.

Clinician-based efforts: changing care delivery

Overall, the centre has changed the way that they deliver care.

> *It is a whole shift in the way that we are working. And it is a huge shift because it is a totally different way of thinking about treatment, it really is from passive to active. We have become so much more active in the organisation of service delivery than we have ever been. That is a huge difference from 5 years ago.* (Interview 3 with project director)

The changes in the delivery of care impact how disease management is enacted, as well as how self-management is viewed and used at the centre. Through the disease management programme, the types of care provided, clinician roles and patient roles have all changed. The types of care provided are now broader, focusing on reaching clients in non-traditional spaces (online, through outreach to youth workers, through email) and emphasising self-management through these new spaces, new means of care and through new roles for healthcare professionals and patients. Healthcare professionals can interact with patients in a solely online world, serve as educators and motivators and coordinate care delivery with a wide variety of professionals, the patients, volunteers and family members. Patients can now be online only patients, educated and motivated patients who decide the course and content of their treatment, self-managed patients who use tools gathered online, from healthcare professionals and from the expert patient support to manage their eating disorder and inspired by automated email messages into (hopefully) healthier bodies and minds. All of these changes result from approaching eating disorders from a disease management framework.

4.1.2 Diabetes management in Zeist

The GP Cooperative in Zeist is a cooperative of general practitioners in Zeist. The Cooperative has worked on improving diabetes care for patients since 1999; according to a GP involved in this work, the early efforts of the GP Cooperative were directed towards moving diabetes care from hospital and specialist based care to primary care, working in cooperation with the hospital and specialists, developing care protocols and contracting with providers. Around 2006, the diabetes care provided by the GP Cooperative was formalised as a chain of care project. As noted in the project plan, the funded disease management programme is a continuation of a project that had been funded by ZonMw in the past; the prior project allowed for the hiring of an external project leader and focused on the development and implementation of electronic medical record systems.

For the purposes of this report, the description focuses on one of the projects conducted within the cooperative: a diabetes disease management programme. The aim of the diabetes program, according to the GP Cooperative website, is:

> *Within the collaborative care group, the care providers have assembled a care program. It has been agreed who will deliver what proportion of total treatment, how to refer [patients] to each other, how care is assessed and how care is constantly adjusted to the latest scientific knowledge, all in the serves of even better coordinated care for your treatment.*
> (Zeist website)

To meet the goals of more collaborative care for patients with diabetes, the project leader and stakeholders at the GP Cooperative in Zeist have endeavoured to change how healthcare professionals work together to deliver care to patients, what is expected of patients and how care is documented. These changes have come through clinician-based efforts, such as working with healthcare professionals to change how they think about care for those with a chronic condition and creating multidisciplinary care teams, implementing a new information system in the form of a networked electronic medical record system with a patient portal and educating patients to self-manage their diabetes. The changes in care, based on disease management principles, result in changes in how care is conceptualised and the locations of care.

> *Clinician-based efforts: changing professional roles*

For patients with diabetes, healthcare professionals move from a position of curing to one where they encourage patients to manage illness. The project leader noted that this would mean that healthcare professionals must 'switch' from their formerly routine manner of providing care during a visit in the doctor's office to one of providing patients with tools to manage their own chronic disease outside of the doctor's office and over a longer period of time.

> *But what's also necessary is that the caregivers themselves, the doctors, the physicians, the nurses, they have to make a switch in not only being a healthcare giver but being a coach, being able to give the support to the patient that they can make their own self-management system and that they can make their own choices and that will really make a difference, instead of the choice of the healthcare giver.* (Interview 1 with first project leader)

By adopting the role of a 'coach', the role of the 'healthcare giver' changes to include supporting patients to make their own 'system' and to make 'their own choices'. In coaching patients, healthcare professionals are trying to motivate patients to make decisions about their own care, to make changes in lifestyle to reduce or manage chronic disease symptoms and to take a different role in their own care through asking questions, participating in educational activities and by using self-management tools. To learn how to coach patients, healthcare professionals had the opportunity to take classes in motivational interviewing. As a coach, the clinician talks with patients, whereby the clinician works with a patient to set personalised goals for lifestyle change, attempts to share decision making and tries to encourage the patient to adopt specific self-management-related behaviours, such as quitting smoking, increasing physical activity, losing weight, or consistently taking medication.

Clinician-based efforts: creating multidisciplinary care teams

There are also changes in professional interactions with one another. The diabetes program at Zeist has created cooperative multidisciplinary care teams for patients with diabetes. The care teams include nurse specialists, nutritionists, general practitioners, nurses, chronic disease practice assistants, ophthalmologists, podiatrists and/or internists. The care team works together, communicating with each other frequently through formal and informal means.

> *I think that working closely with the dietician especially... We sit together, we discuss a lot and we can call the GP or practice nurse and yes, several people are looking [at the case].* (Interview with diabetes specialist nurse)

While the dietician and nurse specialist sit together at the hospital, as do GPs and practice nurses at the GP practice, communication and working as a multidisciplinary care team is not limited to day-to-day interactions in the workplace, but also happens at regular meetings of the entire diabetes care team, through written and emailed reports from the project leader on patient care, through the networked electronic medical record[1], or via meetings with special speakers on relevant topics (such as care of persons with diabetes who observe Ramadan).

While the multidisciplinary care team was established before the implementation of the grant-funded disease management programme, new aspects of the disease management programme have

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[1] Keteninformatiesysteem (KIS)

increased the cooperation and communication between various care professionals. One example is the use of a monitored web-based forum where professionals can give one another advice and learn from specific cases.

> *Finally, we have a forum on the site that makes it interactive. Because otherwise it is only: I can read something, I can look up something. Through the forum, one can, for example, a person with diabetes whose values have been getting worse and you have tried everything and nothing works, just an email to the forum, 'guys, this is the situation, an HB and an HC of…; this I have done, that I have done and that I have done and nothing helps. What now?* (Interview 1 with second project leader)

Through posting questions and advice on the forum, healthcare professionals are forming a network of care, made up of associations and linkages between care providers, patients, the project leader and the computers used in the postings. According to the project leader who monitors the forum, it is fairly active, with healthcare professionals posting different questions or anecdotes. The project leader assists healthcare professionals with technical issues on the forum and posts general announcements and updates; her work strengthens the caregivers' collaboration by making the associations both feasible and relevant. Care becomes located in the care team, in part through the forum used by the healthcare professionals and managed by the project leader.

Information systems: Electronic Medical Record

The development and implementation of the networked electronic record has been a lengthy process for the project; in 2006, the GP Cooperation began working with software developers to develop and implement a limited electronic medical record. The process was complicated by the financial difficulties of the developers, by the incorporation of the company by another software development firm and by the changing needs of the GP Cooperation, including the need for data extraction and for reporting. As stated in the proposal, one of the goals of the project was to complete the development of the ICT infrastructure, as the previous software program did not meet the needs of the project in regard to multidisciplinary cooperation and patient participation and would require further development, including the development of a patient portal.

During the project period, the networked electronic medical record was enhanced. Through the networked electronic medical record, multiple healthcare professionals can view the record, leave messages to other healthcare professionals, refer the patient to other services and monitor the documentation of the patient's interactions with other healthcare professionals.

> *Yeah, so in principle, I can [write] in the whole file and in the diabetic file. And I can open up the diabetes file for other healthcare professionals: the optometrist, the dietician, the podiatrist, the physical therapist, the diabetic specialist nurse. What's needed. And that is pretty easy; it gives patients a bit of security that their private information, their privacy is well respected. Otherwise anyone anywhere can look in.* (Interview with practice nurse)

In the project period, the development and implementation of an online patient portal was completed. Although this offers patients the opportunity to be directly involved, Zeist recognises that few actually do at this time.

Yes, we do have that but no-one uses it. We have talked and talked, to get people to, look, you have your own care file, your own plan, we can agree on goals there, you can report on how it is going, you can also tell us what does not go well, or if you have questions. Really easy, you can do that from your chair at home, you don't have to come here if you don't want to. But people don't want that. It has cost money, because in order to offer the portal we had to expand our software package. Of the current 2700 people with diabetes I believe 15 now have a care plan. (Interview 1 with second project leader, diabetes project)

While patients at Zeist have the option of care online, it is not an option that resonates with patients at this time, though that is hoped to change. The low rates of patient participation in the patient portal were somewhat foreshadowed by the first project leader early in the project, as she noted that few of the older diabetes patients have access to the internet. The patient portal was developed, in part, with future patients in mind; the project leader noted that the younger patients have access to the internet and expected that future diabetic patients will be more likely to have access to and use the internet, including the patient portal. For those patients who do not use the portal, they have access to their care plan through meetings with the nurse, through printed materials and through telephone consultations with care providers. The access to information was tailored to the needs of the patient.

Self-management

In addition to adjusting professional practice and attempting to engage patients through motivational interviewing and providing access to their medical records, the disease management project at Zeist also focused on self-management through educating patients about diabetes. There were a variety of formal and informal educational opportunities for patients: group classes, clinical visits and online via the patient portal, where patients can connect with healthcare professionals and review their care plan.

Through two mornings, patients are educated about diabetes, the risks, nutrition, medication. The principle is that you don't impose anything [on the patients] but if you make people responsible for their illness through self-management, it works better. (Interview 1, medical professional, diabetes project)

As the above quote illustrates, the diabetes project included voluntary group classes with a nurse, doctor and/or non-physician chronic disease specialist assistant. Through the classes, which were open to all diabetic patients (but focus on skills for the newly diagnosed), the patients were disciplined to be their own clinician and manage their diabetes, through working to set and record goals and through learning how to keep logs of carbohydrates and blood glucose readings taken at home. The classes were interactive, with course leaders promoting discussion on different topics. Patients were encouraged to bring family and to ask questions about, for example, diabetes in general, self-management for one's personal situation, or medication options. At the observed training, patients were given notebooks filled with information about carbohydrates, food substitutions, exercise and various forms to be filled in by the patient, including forms for setting goals (which were completed in the first training), glucose logs and charting materials and food journals. Through the training and with the help of the clinician educators, patients were taught to "do" diabetes, to understand their disease, the treatment options available and to tailor their

lifestyle to the best management possible. As seen in the observation of the training, the patients actively participated in the discussion, asking questions and making suggestions for one another.

While the healthcare professionals and project leaders were enthusiastic about the education course, the reaction of the patient population at the start of the project was unknown. While patients who attended the first session were seen as enthusiastic, poor weather forced the cancellation of the second session. One of the GPs heavily involved in the project and education course took a 'wait and see' attitude toward patient population response to the course, noting that the course was best for patients who were interested. However, by the end of the project period, the classes were stopped due to poor attendance by patients.

In the diabetes project in the GP Cooperative in Zeist, it is possible to see how a disease management programme has grown and developed over a longer period of time, as the project work was a continuation of prior disease management efforts. The ways in which care is delivered has changed, with healthcare professionals working in closer multidisciplinary care teams (as facilitated by the networked electronic medical record, by meetings, by the clinician forum), by the educational opportunities that had been provided and by healthcare professionals working as patient coaches to help patients self-manage their illness. The project team at Zeist can be seen as tailoring their project work to the (expected) needs of the current and future patient populations, such as in the offering of a self-management class (and the later stopping of the class, based on the low turn-out by patients), in the development of patient portal for (primarily future) patients and in the education offered to healthcare professionals on patient issues (diabetic patients and Ramadan, for example).

4.1.3 Cardiovascular disease management in Nijmegen (Radboud)

The disease management programme conducted in Nijmegen focuses on the improvement of care for patients with elevated risk of cardiovascular disease. The project was led by two physicians; day-to-day management and administration was handled by a nurse manager. As noted in the grant proposal:

> *The key elements of the implementation project are:*
> 1) *a patient choice program to promote a commitment to the formulated treatment goals*
> 2) *a focus on reaching people who are low SES*
> 3) *the use of a web-based patient record* (Grant proposal)

By researching the implementation of the project conducted in Nijmegen, we have the opportunity to better understand what disease management programmes mean in practice when the population targeted is of a lower socioeconomic level, as well as the impact of a networked electronic medical record.

> *Clinic-based efforts: Serving a low SES patient population*

The disease management project in Nijmegen focused on a difficult to reach population: patients with an elevated cardiovascular risk in a lower socioeconomic level.

> *We have many patients, about 20% of the patients in the GPs practices, is known to the GP as one form of elevated cardiovascular risk. That's a very big number of patients. Of those*

patients, about 8 or 9% are under regular control of the GP. And from those, is a small part of low SES. Especially patients at low SES do not follow our advice. You can see that as you look at the numbers. Most people, more people at the low SES, dying of cardiovascular diseases, more people smoking. People who have an unhealthy lifestyle. So we want to change something in lowering cardiovascular risk, so we have to look at patients who are at elevated risk. That's the most important start of our project. And we don't reach people with low SES, so we are looking at new methods of treatment of people with low SES. That was our intention when we started the project. Then we saw the chronic care model and I was a member of the subcommittee who made the new guideline, the care standard. And that's one part. And the other part, the practice in Nijmegen and the practice in Doesburg, we are one of the 9 practices belonging to the academic research network of practices in the environment of Nijmegen, so we are used to registering everything in our practice, better than general GPs do. (Interview 1 with project leader)

The primary project leader for this project saw the chronic care model, as well as the new care standard, as a method of reaching low SES patients. Through the implementation of the chronic care model, the project leader saw the opportunity to address patient needs on a deeper level, especially in relation to the lifestyle factors that impact cardiovascular risk.

And then another thing was the chronic care model is a patient centred model. And we are not used to working patient centred. It's coming more and more. What's new in our system is that we chose to a patient centred working. And therefore we use the stages of change model ask first to the patient, 'do you want to change something in your lifestyle?' I will show you the ICT project. When the patients say yes, which risk factor do you want to change? Because you can't always change all the factors. You have to choose for one factor. Which risk factor do you chose? The patient can chose for stop smoking, healthy food. Or more movement. Then when the patient has chosen one risk factor, we make a plan. Okay, you would like to stop smoking. How do you want to do that? Then we make a plan. Okay, the next three months, I'll try to stop smoking. I promise you I'll stop… (Interview 1 with project leader)

The focus on the patient and patient's lifestyle is a change for both the patient and the clinician. This change requires an organisational change in how healthcare is delivered and in what is asked of patients. The organisational changes were made through the offering of educational courses, through gathering feedback from healthcare professionals and incorporating it into the disease management programme and through offering support. The changes start:

By organising meetings. That's why we start 4 meeting and why we start at practice level. Speak with the GPs and the nurses. And we have learned to start slowly, go slowly. I will not tell my GPs to start with 100 patients but will tell my GPs we will start very slowly. We will start with 1 patient, then we will evaluate this patient, then we will start with 2, evaluate the second and so forth and so on. And we think that the first 4 or 5 patients will be very difficult. They will see various things that are not well developed by us, but after 5 or 10 patients, we hope that it will go very well by us and we will have reached our 100 patients within some months… When we make the evaluation, we have to ask them for the barriers. And we have to say okay, this is what you were not so happy with – we have to change this. We have to

listen to our GPs, we have to listen to the people who are working in the daily practice. They are not scientists. But they are workers so we have to listen to them very well.

[We get] feedback, also. But the feedback we cannot get after 4 or 5 patients. But I can convince them by telling them that we will have an evaluation of the project and can conclude may conclude that after the evaluation after 2 years that it doesn't work, then we have to go the same way as we do now. But if it works, we have to change the practice. I hope it works. But we have to wait for it still. (Interview 1 with project leader)

The organisational changes were seen to take time, to take energy and to need the support and buy-in of the healthcare professionals who were to actually implement the changes at the patient level. As seen in other projects, this background work was understood to be necessary to change care for those with a chronic condition and comes a form of care itself, even before the patient is able to see the changes in care for their chronic condition.

However, despite the efforts of the project leadership team, there were still challenges as the project progressed.

Well, you've got to separate the problems: content level and organisational level. Content, I think, it actually runs smoothly. We must, of course, continue to develop, but that is going how we want. Organisationally we have some problems. Practices are, of course, very large organisations now. So before we begin, we have to convince everyone of the importance of the research. That takes a lot of effort. Plus the implementation of such a project, in practice is not simple because practices are large organisations where 30 people work. Plus there are other members of the care group that need to be involved: the physiotherapist, the dietician. What is we find now is a missed opportunity to work with the pharmacist. No contact. I think, really, that it is a missed opportunity. We simply forgot. So maybe we can make that a little better. (Interview with the project team)

These challenges included working with large groups, connecting and contracting with different types of healthcare professionals and in involving all of the potentially beneficial stakeholders in the project. Treatment, then, becomes as much an organisational feat as it is a clinical endeavour.

The changes involved in the disease management programme changed the expectations of healthcare professionals and patients, with an emphasis on patient-centred care. According to the project leader, the patient has more of a voice in their care plan:

We (healthcare professionals) are used to asking the patient to come to the practice 4 times a year, or 1 times a year or 6 times. But maybe the patient has another form. So we will ask the patient how to care for him or her the best. (Interview one with project leader)

However, the low-SES patient population is seen to be a challenging one, with many barriers for addressing elevated risk of cardiovascular disease.

Yes, we have a lot of immigrants in the area and we are still a bit of a deprived area, I feel. We are not often seen by insurers as a deprived area with a lot of immigrants but also patients with a lower SES and lower income. You notice that if patients need to exercise a lot,

many people smoke and there are also those who smoke who also want to get rid of other additions like alcohol and drugs. (Interview 1 with chronic disease specialist assistant)

To be overcome, these challenges require effort on the part of the patient, effort at changing lifestyle factors, effort to work with healthcare professionals and effort to address underlying issues that impact their health. Effort is also required of the healthcare professionals, who must work with and around deeper problems, must learn to work with patients who may speak minimal Dutch and work with patients who may not have the resources expected of other patients. This requires accommodation on the part of the clinician and of the patient.

Information systems: Electronic Medical Record

As was seen in other projects, the development of the networked electronic medical record was a lengthy process. In this project, it required close working relationships with the developer and with health insurance providers.

> *And for the development of cardiovascular risk management, this is how far we are now: we have funding. We are now working with contract negotiations. And then we can start developing and the ICT supplier, if they are fast, can get us a better version in three months' time. We hope that we really can start with ICT in March, February… well, of course it is a problem to get financing. A negotiation problem. Yes, but we are happy that we have had luck.* (Interview with the project team)

As health insurance providers provided some of the financing needed for the development and implementation of the networked electronic medical record, there was much coordination work needed. Health insurance providers required extensive plans, budgets and presentations before financing was awarded. Developing and implemented a networked electronic medical record is a process of coordination, negotiation, documentation and adaptation over time with multiple actors involved.

The networked electronic medical record in the Nijmegen project included a planned patient portal, in which patients can log into the record and see their own file. The patient's treatment plan will exist in the record, able to be seen by the patient and their various healthcare professionals.

> *It will work the same way but [for] the patient with low SES cannot use a computer, we use paper. The patient will have a paper file but we will have to put everything in. In our file, in the patient's file. The data of the patient, we put it in the patient file, but the patient cannot look at his own screen. The treatment is the same.* (Interview with project leader)

Lack of access to a computer or the internet was not seen as a barrier to care. For the patients who cannot access their record on the internet, a paper version can be printed out. In regard to the patient portal, care was expected to be tailored to the needs of the patients.

In the disease management programme for patients with elevated risk of cardiovascular disease in Nijmegen, it is possible to see the early development and implementation of a disease management program for a tricky population. By focusing on the needs of the patients and involving patients more in their own care, the project leader hoped to improve care for patients. However, it was seen to be challenging to ensure clinician involvement in the changes in care, requiring that project

leadership team listen to the feedback from healthcare professionals and adapt accordingly, as well as adapting to the needs of the patients. This project also gives insight into the process of developing a networked electronic medical record, including the work required to get funding and to adapt the record to the needs of the population.

Chapter 5: Improvements in quality of chronic care delivery

The average baseline (T0) quality of chronic care delivery for all disease management programmes ranged from 5.93 (integration of care components) to 7.36 (delivery system design), indicating basic to intermediate/advanced support for chronic illness care. One year later (T1), average quality of chronic care delivery scores were considerably higher; they ranged from 6.52 (integration of care components) to 8.10 (delivery system design), indicating advanced support for chronic illness care. Two years after implementing changes in care practice (T2), average quality of chronic care delivery scores for the disease management programmes had increased further; they ranged from 7.02 (integration of care components) to 8.67 (delivery system design), indicating a higher degree of advanced support for chronic illness care than at T1.

Overall quality of chronic care delivery scores documented significant improvement in chronic care delivery in the first year after the implementation of these disease management programmes (paired t-test, $p < 0.001$; table 5.1). Specifically, the most significant improvements were made in self-management support, delivery system design and the integration of chronic care components (all $p < 0.001$). The organisation of the healthcare delivery system and clinical information systems also showed significant improvement (both $p < 0.01$), as did decision support ($p < 0.05$). The only component of the chronic care model that did not show significant improvement in the first year after program implementation was community linkages (Cramm and Nieboer 2013a).

Table 5.1 First-Year Changes in the Quality of Chronic Care Delivery, as Measured by Assessment of Chronic Illness Care Short Version (ACIC-S) Scores

	Baseline (T0[a]) assessment		Follow-up (T1[b]) assessment		Change in score (T1 − T0)			
	M[c]	SD[d]	M	SD	M	SD	P[e]	n
Organisation of the healthcare delivery system	7.11	(1.20)	7.51	(1.68)	0.40	(1.98)	<0.01	149
Community linkages	6.51	(1.78)	6.72	(1.76)	0.19	(1.89)	0.214	148
Self-management support	6.10	(2.19)	6.71	(2.00)	0.61	(2.27)	<0.001	151
Decision support	6.73	(1.76)	7.03	(1.70)	0.30	(1.52)	<0.05	150
Delivery system design	7.36	(1.57)	8.10	(1.70)	0.74	(1.65)	<0.001	151
Clinical information systems	6.16	(1.93)	6.57	(1.72)	0.41	(1.73)	<0.01	143
Integration of chronic care components	5.93	(1.93)	6.52	(1.72)	0.59	(1.92)	<0.001	145
Overall quality of chronic care delivery[f]	6.56	(1.50)	7.05	(1.38)	0.49	(1.27)	<0.001	154

[a]T0, 2010; [b]T1, 2011; [c]M, mean; [d]SD, standard deviation. [e]Paired t-test, T0 vs. T1. [f]Scores indicate: 0–2 (little or no support for chronic illness care), 3–5 (basic or intermediate support), 6–8 (advanced support) and 9–11 (optimal or comprehensive integrated care for chronic illness). These analyses included respondents who completed questionnaires at measurement points T0 and T1 only (n = 154). Table from publication Cramm and Nieboer 2013a.

Table 5.2 displays the changes in the quality of chronic care delivery in the second year after program implementation, as measured by ACIC-S scores. These scores also showed significant improvement in chronic care delivery compared with scores obtained at baseline and after the first year of implementation (paired t-test, $p < 0.001$; Table 5.2). However, the areas in which improvements were made differed somewhat from those most affected in the first year. The most significant improvements were made in delivery system design, clinical information systems and community linkages (all $p < 0.001$), the latter of which showed no improvement in the first year. Decision support and the integration of chronic care components showed continued improvement (both $p < 0.01$), as did self-management support ($p < 0.05$). The only component of the chronic care model that did not improve significantly between the first and second year after implementation was the organisation of the healthcare delivery system, although this aspect had been improved within the first year of disease management programme implementation. We also investigated changes between baseline (T0) and 2012 (T2), as measured by ACIC-S scores. These scores showed significant improvement in all areas of the chronic care model (Cramm and Nieboer 2013a).

Table 5.2 Second-Year Changes in the Quality of Chronic Care Delivery, as Measured by Assessment of Chronic Illness Care Short Version (ACIC-S) Scores

	Follow-up (T1)[a] assessment		Follow-up (T2)[b] assessment		Change in score (T2 − T1)			
	M[c]	SD[d]	M	SD	M	SD	P[e]	n
Organisation of the healthcare delivery system	7.57	(1.74)	7.72	(1.84)	0.15	(1.84)	0.301	159
Community linkages	6.84	(1.80)	7.54	(1.69)	0.70	(1.82)	<0.001	161
Self-management support	6.88	(1.86)	7.19	(1.86)	0.31	(1.79)	<0.05	168
Decision support	7.18	(1.68)	7.50	(1.51)	0.32	(1.51)	<0.01	168
Delivery system design	8.27	(1.54)	8.67	(1.38)	0.41	(1.52)	<0.001	167
Clinical information systems	6.81	(1.65)	7.34	(1.64)	0.53	(1.61)	<0.001	164
Integration of chronic care components	6.68	(1.75)	7.02	(1.59)	0.34	(1.66)	<0.01	166
Overall quality of chronic care delivery[f]	7.16	(1.36)	7.55	(1.29)	0.39	(1.09)	<0.001	170

[a]T1, 2011; [b]T2, 2012; [c]M, mean; [d]SD, standard deviation. [e]Paired t-test, T1 *vs*. T2. [f]Scores indicate: 0–2 (little or no support for chronic illness care), 3–5 (basic or intermediate support), 6–8 (advanced support) and 9–11 (optimal or comprehensive integrated care for chronic illness). These analyses included respondents who completed questionnaires at measurement points T1 and T2 only (n = 170). Table from publication Cramm and Nieboer 2013a.

Overall, this research clearly showed that the quality of care chronic care delivery improved over time. In addition, we saw that the disease management programmes included in the T3 measurement (2013) were able to sustain these improvements.

Chapter 6: Patient outcomes

At baseline 47% of the respondents were female, 38% had a low educational level and 29% were single. Mean age was 64.8 ± 10.5 (range, 20–98) years (Table 6.1).

Table 6.1 Background characteristics of patients at Baseline (T0) n=2807

	Gender (female)	Age	Marital status (single)	Educational level (low)
	%	Mean (sd)	%	%
Onze Lieve Vrouwe Gasthuis (CV-DMP)	44%	67,2 (10.5)	46%	40%
De Stichting Eerstelijns Samenwerkingsverband Achterveld (CV-DMP)	40%	63,8 (8.6)	11%	45%
Regionale Organisatie Huisartsen Amsterdam (CV-DMP)	36%	65.1 (8.0)	35%	38%
De Stichting Gezondheidscentra Eindhoven (CV-DMP)	56%	63.3 (10.4)	26%	41%
Gezondheidscentrum Maarssenbroek (CV-DMP)	56%	59.7 (9.6)	23%	29%
Rijnstate (CV-DMP)	54%	63,2 (10.3)	21%	45%
Medisch Centrum Oud-West (CV-DMP)	55%	60.7 (11.0)	30%	45%
Universiteit Medisch Centrum St. Radboud (CV-DMP)	47%	67,6 (11.0)	28%	42%
Wijkgezondheidscentra Huizen (CV-DMP)	32%	65.8 (10.2)	26%	30%
HAFANK (Hartfalen Noord Kennemerland) (Heart failure DMP)	41%	78.5 (8.8)	43%	50%
Huisartsencoöperatie Midden-Brabant (COPD DMP)	45%	64.7 (11.4)	34%	56%
Archiatros (COPD DMP)	46%	65.9 (10.5)	34%	52%
Stichting Gezond Monnickendam (COPD DMP)	53%	67,5 (9.0)	33%	35%
Zorggroep Almere (COPD DMP)	43%	66.7 (10.0)	34%	47%
Huisartsen Coöperatie Zeist (Diabetes DMP)	45%	66.0 (9.7)	24%	25%
Zorggroep Haaglanden (Diabetes DMP)	45%	62.1 (10.2)	39%	25%
Gezondheidscentrum De Roerdomp (Diabetes DMP)	41%	64.1 (11.0)	35%	25%
Chronische Ketenzorg Land van Cuijk en Noord Limburg BV (Co morbidity DMP)	42%	68,2 (9.9)	24%	41%
Total of all DMPs	47%	64.8 (10.5)	29%	38%

Notes: DMP, Disease Management Programme. SD, Standard Deviation.

6.1 Short-term effects on health behaviours and quality of life

Overall, patients' self-reported physical activity scores improved significantly from T0 (mean, 4.93) to T1 (mean, 5.23; *p* < 0.001). This improvement was seen within the cardiovascular, COPD as well as the diabetes disease management programmes (Table 6.2) (see Appendix Chapter 6 (1 - 4) for overview of short-term effects within each disease management programme).

Table 6.2 Short-term effects on health behaviours and quality of life

	Baseline (T0; 2010)		Follow-up (T1; 2011)		Short-term change			
	M	SD	M	SD	M	SD	p^a	n
Mental quality of life								
Within cardiovascular DMPs	50.14	(9.50)	49.42	(9.62)	-0.72	(7.97)	0.019	682
Within COPD DMPs	48.27	(10.48)	46.93	(10.36)	-1.33	(9.18)	0.005	371
Within Diabetes DMPs	50.78	(8.63)	49.76	(9.06)	-1.02	(6.94)	0.043	193
Co morbidity DMP	52.89	(7.92)	49.91	(8.56)	-2.98	(8.32)	0.001	97
Heart failure DMP	46.91	(6.91)	50.24	(7.24)	+3.33	(8.53)	0.116	18
Total	49.89	(9.58)	48.81	(9.71)	-1.08	(8.20)	<0.001	1361
Physical quality of life								
Within cardiovascular DMPs	44.04	(9.97)	43.44	(10.00)	-0.60	(7.04)	0.026	682
Within COPD DMPs	39.55	(9.66)	38.71	(9.88)	-0.84	(6.96)	0.021	371
Within Diabetes DMPs	43.50	(9.91)	42.71	(9.94)	-0.79	(6.39)	0.089	193
Co morbidity DMP	42.34	(10.20)	41.75	(10.04)	-0.59	(6.37)	0.361	97
Heart failure DMP	34.89	(10.10)	31.10	(12.50)	-3.79	(8.99)	0.091	18
Total	42.51	(10.09)	41.75	(10.26)	-0.76	(6.95)	<0.001	1361
Physical activity								
Within cardiovascular DMPs	5.00	(2.07)	5.33	(1.85)	+0.33	(2.15)	<0.001	535
Within COPD DMPs	4.83	(2.13)	5.17	(2.05)	+0.33	(2.21)	0.008	308
Within Diabetes DMPs	4.74	(1.94)	5.03	(1.85)	+0.29	(2.01)	0.073	154
Co morbidity DMP	5.15	(1.97)	5.25	(1.90)	+0.10	(1.81)	0.630	84
Heart failure DMP	5.30	(2.21)	5.20	(2.30)	-0.10	(2.47)	0.901	10
Total	4.93	(2.06)	5.23	(1.92)	+0.30	(2.13)	<0.001	1091

	%			%			p^b	n
Current smokers								
Within cardiovascular DMPs	20			15			<0.001	679
Within COPD DMPs	38			30			<0.001	366
Within Diabetes DMPs	20			14			0.002	191
Co morbidity DMP	8			6			0.625	91
Heart failure DMP	15			15			1.000	20
Total	24			18			<0.001	1347

Notes: M, mean; SD, standard deviation; DMP=Disease Management Programme. [a]Paired *t*-test, T0 *vs*. T1. [b]McNemar chi-square tests, T0 *vs*. T1. Analyses included respondents who completed questionnaires at both T0 and T1.

The percentage of self-reported current smokers decreased significantly (24% *vs*. 18%; $p < 0.001$). Again, this improvement was seen within the cardiovascular, COPD and diabetes disease management programmes. The percentage of smokers at T0 is much higher among COPD patients (38%) compared to patients with diabetes (20%) and cardiovascular conditions (20%).

Looking at short-term effects on quality of life, results show that patients' physical quality of life decreased significantly from T0 (42.51) to T1 (41.75) ($p < 0.001$). This decline took place within the cardiovascular and COPD disease management programmes. The reduction in physical quality of life within the diabetes disease management programmes was not significant. Physical quality of life of

COPD patients at T0 (39.55) is lower compared to patients with diabetes (43.50) and cardiovascular conditions (44.04).

Mental quality of life also reduced significantly from T0 (49.89) to T1 (48.81) ($p < 0.001$). This decline was evident within the cardiovascular, co morbidity, COPD and diabetes disease management programmes. COPD patients reported lower mental quality of life at T0 than diabetic patients and those with cardiovascular conditions.

Changes in health behaviours (smoking and physical activity) and quality of life (mental and physical) did not differ significantly between patients with or without co morbidity.

6.2 Long-term effects on health behaviours and quality of life

Looking at long term benefits (2012 versus 2010) results show that patients' physical activity scores improved significantly from T0 (mean, 4.93) to T2 (mean, 5.61; $p < 0.001$). This improvement took place within the cardiovascular, COPD and diabetes disease management programmes.

The percentage of current smokers decreased significantly (24% *vs*. 19%; $p < 0.001$). Again, this improvement was seen within the cardiovascular, COPD and diabetes disease management programmes (Table 6.3).

While short-term effect showed a reduction in physical quality of life, the long-term effect showed that patients' physical quality of life improved significantly from T0 (mean, 42.41) to T2 (mean, 44.03; $p < 0.001$). This improvement was seen within the cardiovascular, COPD and diabetes disease management programmes.

While the long-term effects on physical quality of life were positive, the disease management programmes were not able to improve patients' mental quality of life. Mental quality of life reduced significantly from T0 (49.78) to T2 (48.63) ($p < 0.001$). This decline was significant within the cardiovascular and COPD programmes, but not within the programmes aimed at diabetic patients (see Appendix Chapter 6 (5 - 8) for an overview of long-term effects within the disease management programmes).

Table 6.3 Long-term effects on health behaviours and quality of life

	Baseline (T0; 2010)		Follow-up (T2; 2012)		Long-term change			
	M	SD	M	SD	M	SD	p^a	n
Mental quality of life								
Within cardiovascular DMPs	50.09	(9.44)	49.05	(9.65)	-1.04	(8.21)	0.005	507
Within COPD DMPs	48.38	(10.50)	46.85	(10.30)	-1.53	(9.86)	0.004	344
Within Diabetes DMPs	50.81	(9.01)	49.98	(8.40)	-0.84	(8.43)	0.203	166
Co morbidity DMP	51.52	(9.14)	50.37	(8.52)	-1.15	(7.80)	0.160	92
Heart failure DMP	48.63	(6.13)	50.30	(6.22)	+1.67	(5.56)	0.395	9
Total	49.78	(9.71)	48.63	(9.64)	-1.15	(8.73)	<0.001	1118
Physical quality of life								
Within cardiovascular DMPs	44.34	(9.92)	45.55	(8.68)	+1.20	(7.02)	<0.001	507
Within COPD DMPs	39.70	(9.93)	42.13	(8.56)	+2.44	(7.36)	<0.001	344
Within Diabetes DMPs	43.00	(10.30)	44.57	(9.03)	+1.57	(7.24)	0.006	166
Co morbidity DMP	41.30	(10.61)	42.46	(8.85)	+1.16	(6.42)	0.086	92
Heart failure DMP	37.94	(10.13)	37.10	(12.69)	-0.84	(7.02)	0.728	9
Total	42.41	(10.23)	44.03	(8.89)	+1.62	(7.12)	<0.001	1118
Physical activity								
Within cardiovascular DMPs	4.95	(2.13)	5.64	(1.78)	+0.70	(2.26)	<0.001	404
Within COPD DMPs	4.81	(2.09)	5.46	(1.91)	+0.66	(2.22)	<0.001	281
Within Diabetes DMPs	4.84	(2.02)	5.68	(1.66)	+0.85	(1.88)	<0.001	136
Co morbidity DMP	5.39	(1.86)	5.82	(1.69)	+0.42	(2.15)	0.092	76
Heart failure DMP	5.75	(1.89)	6.50	(0.58)	+0.75	(1.50)	0.391	4
Total	4.93	(2.08)	5.61	(1.79)	+0.68	(2.18)	<0.001	901

	%		%		p^b	n
Current smokers						
Within cardiovascular DMPs	17		14		0.009	519
Within COPD DMPs	41		31		<0.001	343
Within Diabetes DMPs	20		15		0.022	169
Co morbidity DMP	8		8		0.500	99
Heart failure DMP	18		36		0.500	11
Total	24		19		<0.001	1141

Notes: M, mean; SD, standard deviation; DMP=Disease Management Programme. [a]Paired *t*-test, T0 *vs*. T2. [b]McNemar chi-square tests, T0 *vs*. T2. Analyses included respondents who completed questionnaires at both T0 and T2.

Changes in health behaviours and mental quality of life were not statistically different between patients with or without co morbidity. Long term changes in physical quality of life did vary significantly; greater improvements were found in patients with co morbidity (+2.6 versus +0.3). Physical quality of life of co morbidity patients was much lower at baseline (38.35) than those without co morbidity (47.50). At T2 this gap in physical quality of life became smaller.

6.3 Sustainability

In 2013, we investigated health behaviours and quality of life among a selection of the 22 disease management programmes to see if they were able to sustain their improvements. Overall, these

results show that these disease management programmes were able to sustain improvements in patients' physical activity (5.06 versus 5.64; $p < 0.001$) (Table 6.4), quit smoking among patients (28% *vs*. 21%; $p < 0.001$) and physical quality of life (41.41 versus 42.60; $p < 0.001$). The disease management programmes were still not able to improve patients' mental quality of life (See Appendix Chapter 6 (9 - 12) for an overview of sustainability within 8 disease management programmes).

Table 6.4 Sustainability of effects on health behaviours and quality of life

	Baseline (T0; 2010)		Follow-up (T3; 2013)		Sustainable change			
	M	SD	M	SD	M	SD	p^{a}	n
Mental quality of life	50.03	(9.68)	48.13	(9.88)	-1.90	(7.94)	<0.001	469
Physical quality of life	41.41	(9.81)	42.60	(8.66)	+1.19	(6.72)	<0.001	469
Physical activity	5.06	(1.98)	5.64	(1.83)	+ 0.58	(2.11)	<0.001	404
	%				%		p^{b}	n
Current smokers	28				21		<0.001	476

Notes: M, mean; SD, standard deviation; DMP=Disease Management Programme. [a]Paired *t*-test, T0 *vs*. T3. [b]McNemar chi-square tests, T0 *vs*. T3. Analyses included respondents who completed questionnaires at both T0 and T3.

6.4 Effectiveness of the stroke and 3 mental disease management programmes

We report effectiveness of the stroke and 3 mental disease management programmes separately due to 1) a small sample (<15 patients at SGE depression), 2) different time-frame of data collection (Sint Lucas Andreas) and 3) slightly different questionnaire content to address a specific mental health condition at van Arkel (aimed at patients with psychotic conditions) and Ursula (aimed at patients with eating disorders).

6.4.1 Stroke disease management programme Sint Lucas Andreas

At baseline 40% of the respondents were female, 38% had a low educational level and 30% were single. Mean age was 64.5 ± 10.5 (n=50).

Short-term effects on health behaviours and quality of life

T1 questionnaires were filled in 6 months after baseline. Short-term effects showed no significant changes in physical quality of life (43.21 at T0 *vs*. 44.26 at T1; $p = 0.439$ n=33), mental quality of life (49.61 at T0 *vs*. 48.47 at T1; $p = 0.376$ n=33) or physical activity among stroke patients (4.33 at T0 *vs*. 5.17 at T1; $p = 0.402$ n=26). The percentage of current smokers did decrease significantly (24.3% at T0 *vs*. 16.2% at T1; $p < .001$ n=37).

Long-term effects on health behaviours and quality of life

T2 questionnaires were filled in 12 months after baseline. Long-term effects showed similar results. Again no significant changes were found in physical quality of life (44.39 at T0 *vs*. 45.61 at T2; $p = 0.381$ n=29), mental quality of life (48.36 at T0 *vs*. 47.20 at T2; $p = 0.494$ n=29) or physical activity

among stroke patients (5.70 at T0 *vs.* 5.34 at T2; *p* = 0.489 n=27). The percentage of current smokers was still lower (30.3% at T0 *vs.* 18.2% at T2; *p* < 0.001 n=33).

6.4.2 Psychotic disorders disease management programme Reinier van Arkel

At baseline 56% of the respondents were female, 18% had a low educational level and 41% were single. Mean age was 41.3 ± 10.0 (n=40).

Short-term effects on health behaviours and quality of life

Short-term effects showed no significant changes in physical quality of life (49.14 at T0 *vs.* 45.87 at T1; *p* = 0.135 n=25), mental quality of life (39.10 at T0 *vs.* 41.84 at T1; *p* = 0.215 n=25) or physical activity among patients with psychotic disorders (4.65 at T0 *vs.* 4.90 at T1; *p* = 0.647 n=20). The percentage of current smokers did decrease significantly (47.8% at T0 *vs.* 21.7% at T1; *p* =0.031 n=23).

Long-term effects on health behaviours and quality of life

Long-term effects showed similar results. Again no significant changes were found in physical quality of life (50.46 at T0 *vs.* 48.61 at T2; *p* = 0.356 n=20), mental quality of life (40.53 at T0 *vs.* 44.68 at T2; *p* = 0.112 n=20) and physical activity (4.67 at T0 *vs.* 5.47 at T2; *p* = 0.217 n=15). While short-term effects seemed to have led to a reduction of smoking, no significant reduction in percentage of current smokers was found after a two-year time frame. The percentage of current smokers did not decrease significantly (36.4% at T0 *vs.* 31.8% at T2; *p* = 1.000; n=22).

6.4.3 Eating disorders disease management programme Ursula

At baseline 96% of the respondents were female, 9% had a low educational level and 65% were single. Mean age was 31.5 ± 12.1 (n=119).

Short-term effects on health behaviours and quality of life

Short-term effects showed no significant change in mental quality of life (32.82 at T0 *vs.* 34.07 at T1; *p* = 0.358 n=83). Physical quality of life did improve significantly from 39.76 (at T0) to 47.49 (at T1)(*p* < 0.001 n=83). No significant changes were found in physical activity (4.93 at T0 *vs.* 5.37 at T1; *p* = 0.137 n=71) and the percentage of current smokers (18.8% at T0 *vs.* 20.0% at T1; *p* = 1.000 n=85).

Long-term effects on health behaviours and quality of life

Long-term effects show that mental quality of life marginally improved from 31.62 (at T0) to 34.31 (at T2)(*p* = 0.080 n=58) and physical quality of life was still higher compared to baseline: 40.45 (at T0) and 47.59 (at T2)(*p* < 0.001 n=58). Physical activity improved only marginally (5.12 at T0 *vs.* 5.59 at T2; *p* = 0.098 n=49) and no changes were found in the percentage of current smokers (16.7% at T0 *vs.* 16.7% at T2; *p* = 1.000 n=60).

6.4.4 Depression disease management programme Stichting Gezondheidscentra Eindhoven

Together with ZonMw we decided not to follow patients that suffered from depression with surveys. We used data that was registered in the General Practitioner (GP) registration databases. Patients

diagnosed with depression between January 2008 and December 2011 were included, which resulted in a total sample of 2189 patients. Of these 2189 patients 953 patients were diagnosed with mild depression and 1236 patients with severe depression. Registration of the BDI (=severity of the depression) is part of the disease management programme to determine and monitor severity of the disease. Of the 2189 patients included 355 (16%) patients had at least one BDI registration and were considered as the patients that were treated according to the disease management programme. The rest of the selected patients (n= 1869) were considered to be treated according to care as usual. Antidepressant use, lifestyle indicators and co morbidities in patients with mild and severe depression were analysed over the years for patients in the treatment and control group.

Antidepressant use

Patients that were newly diagnosed with *mild depression* and treated according to the disease management programme increased over the years from 11% to 17% and from 8% to 18% for patients newly diagnosed with severe depression (Schaafsma, 2012). For the newly diagnosed patients with mild depression treated according to the disease management programme 28% received antidepressants in 2008 compared to 9% in 2011. Antidepressant use was defined as using one or more of the following antidepressants: non-selective monoamine reuptake inhibitors (N06AA), selective monoamine reuptake inhibitors (N06AB), non-selective monoamine oxidase inhibitors (N06AF) or other antidepressant (N06AX). This indicates a decrease in antidepressant use over the years. In contrast, for newly diagnosed patients treated according to usual care an increase in antidepressant use was seen from 16% in 2008 to 24% in 2011. Differences in antidepressant use between newly diagnosed patients treated according to disease management programme and usual care were statistically significant in 2011 (*p*=0.025).

In patients with *severe depression*, both for patients treated according to the disease management programme and usual care an increase in antidepressant use was seen for newly diagnosed patients over the years. The increase was 40% to 62% and 46% to 67% for patients treated according to disease management programme and usual care, respectively. The difference between antidepressant use for newly diagnosed patients between treatment groups was not significant.

Lifestyle indicators and co morbidities

Lifestyle indicators were only registered for a small part of the patients, but registration improved over the years both for patients with mild and severe depression. The number of patients with mild depression that stopped smoking was analysed and did not differ between patients treated according to the disease management programme and usual care, except for in 2010. In 2010 significantly more patients stopped smoking when treated according to the disease management programme compared to patients treated according to usual care. For patients with severe depression no significant differences in the number of patients that stopped smoking were present between the two treatment groups.

Furthermore, cholesterol levels, glucose levels and Body Mass Index (BMI) can indicate risk for cardiovascular disease, diabetes and obesity. Average cholesterol levels, glucose levels and BMI were determined for all years for patients treated according to the DMP and usual care to determine if differences in levels existed between the two groups. There were no significant differences between cholesterol or glucose levels for any of the years between patients treated according to the

disease management programme or usual care. There were also no significant differences in average BMI for patients treated according to usual care compared to patients treated according to the disease management programme, except in 2010. In 2010 the average BMI was significantly lower for patients with mild depression treated according to the disease management programme compared to patients with mild depression treated according to usual care. The number of patients that were obese increased in the group of patients with mild depression treated according to usual care but did not differ significantly with the number of obese patients treated according to the disease management programme. For patients with severe depression the number of patients that were obese increased in both treatment groups. There were no significant differences in obesity between the treatment groups.

A decrease in co morbidities (diabetes, anxiety and cardiovascular disease) is seen for both patients with mild and severe depression when treated according to the DMP compared to a steady state for patients treated according to usual care. However, there were no statistical significant differences between the two treatment groups.

Referral behaviour

The number of newly diagnosed patients with mild depression that were referred to a psychiatrist increased from 16% in 2008 to 35% in 2010 and decreased again in 2011 to 28% for patients that were treated according to disease management programme. Patients that were treated according to usual care remained approximately the same around 30% during the years 2008 to 2011. Differences in the number of patients that were referred were not statistically significant for any of the years between the two treatment groups.

Patients that were newly diagnosed with severe depression and treated according to the DMP show an increase in the number of patients that are referred to a psychiatrist from 26% in 2008 to 44% in 2011. Patients treated according to usual care showed a decrease in referrals from 33% in 2008 to 28% in 2010 after which the referrals increased again to 34% in 2011. The difference in referral between patients treated according to DMP and usual care is however not statistically significant for newly diagnosed patients with severe depression.

When all patients treated per year are analysed an increase is seen for patients treated according to the DMP from 26% in 2008 to 44% in 2011 and a decrease is seen for patients treated according to usual care from 33% in 2008 to 27% in 2011. Patients that were treated according to the disease management programme were significantly more often referred to a psychiatrist in 2010 and 2011 than patients that were treated according to usual care.

6.5 Risk factor levels and clinical outcomes

Besides patients' perceptions using questionnaires we also investigated risk factor levels and clinical outcomes based on data registries from the disease management programmes. In most cases the process performance indicators such as % of patients with monitoring tests (e.g. blood tests and spirometry) and % of patients with lifestyle advice were improved. Similarly, outcome indicators such as % of patient with Body Mass Index (BMI) lower than 25 or blood pressure lower than 140 mm Hg, were also improved. However, it should be noted that the calculated numbers are subject to the quality and availability of the delivered data.

As table 6.5 shows, the levels of the risk factors and clinical outcomes changed in most cases in the desired direction. In detail, total cholesterol, glucose, low-density lipids, alcohol use, systolic blood pressure, waist circumference and triglycerids were on average reduced during the follow-up period. However, the Forced Expiratory Volume as percentage of the predicted value (FEV1 % pred.) was slightly reduced in COPD patients at Monnickendam and the hemoglobin A1c (HbA1c) level was increased in diabetic patients at Zeist (Table 6.6).

Table 6.5 Differences in clinical outcomes between time points in Cardiovascular DMPs

Time points	DMP	Total cholesterol	Glucose	LDL	BMI	Alcohol	SBP	Waist circumference	HDL
T1-T0	Maarsenbroek	-0,07	-0,03	-0,06	2,61**		-1,39	-0,61	
	Rijnstate	0,03	0,09	0,04	-0,11	0,16	-5,85**	0,45	
	Radboud	-0,15*	-0,05	-0,22*	1,52*	1,19	0,30	-0,15	
T2-T0	MCOW	0.33	-0.21*	-0.07	0.08	-0.48*	-6.03	-1.08	
	Radboud	-0.18*	-0.03	-0.23**	1.82	0.50	-1.91	0.04	
	Huizen	-0.10	-0.20		-0.07		-2.89		
T3-T0	Huizen	-0.10	-0.20		-0.07		-2.89		
T2-T1	Radboud	-0,07	0,76	-0,03	0,04	0,09	-2,83	-1,10	
T3-T2	Huizen	-0.01	0.02		0.01	0.01*	-0.06	-0.16*	0

*p<0.5; **p<0.01; ***p<0.001; LDL: low-density lipoprotein; SBP: systolic blood pressure; HDL: high-density lipoprotein; BMI: body mass index.

Table 6.6 Differences in clinical outcomes between time points in COPD and diabetes DMPs

Time points	DMP	Total cholesterol	LDL	BMI	Alcohol	Triglyce-rides	FEV1/FVC	FEV1 Pred.	FVC Pred.	MRC	HbA1c
T1-T0	Almere			0,14			-0,86			-0,01	
	Zeist	-0.09		-0.08	-0.24	-0.06*					2.82**
T2-T0	Zeist	-0.08	-0.08	-0.18		-0.03					4.65***
T2-T1	Zeist	-0.02	-0.01	-0.08		0.03					0
T3-T2	Monnickendam			0.38			-2.69	-0.02***	-0.01	-0.02	

*p<0.5; **p<0.01; ***p<0.001; LDL: low-density lipoprotein; BMI: body mass index; FEV: forced expiratory volume; FVC: forced vital capacity; pred.: predicted; MRC: Medical Research Council breathlessness scale; HbA1c: Hemoglobin A1c.

Chapter 7: Costs

7.1 Development and implementation costs

The development and the implementation costs of the first 2 years are presented in Table 7.1. The largest share of these costs is for costs related to the time that personnel dedicates to the implementation of Disease Management Programmes (DMPs). Costs related to educational courses for caregivers and information brochures for patients were low in almost all cases (except in the Diabetes Mellitus Disease Management Programme 1 (DM-DMP1)). In some DMPs "other" costs such as ICT, energy and accommodation costs were relatively high (e.g. 66% in DM-DMP 2).

Table 7.1 Development and implementation costs by disease management programme

	N	Development phase*			Implementation Year 1*			Implementation Year 2*		
		Total costs without amortization #	Costs per patient without amortization	Costs per patient with amortization*	Total costs without amortization #	Costs per patient without amortization	Costs per patient with amortization	Total costs without amortization #	Costs per patient without amortization	Costs per patient with amortization
CV-DMP 1	300	52,136	174	35	16,426	55	90	-	-	-
CV-DMP 2	207	54,417	263	53	68,415	331	381	65,079	314	365
CV-DMP 3	700	98,754	141	28	153,215	219	234	112,686	161	176
CV-DMP 4	300	274,783	916	183	171,026	570	605	176,068	587	622
CV-DMP 5	550	26,807	49	10	67,604	123	142	92,286	168	187
CV-DMP 6	450	27,923	62	12	149,990	333	356	122,432	272	295
CV-DMP 7	125	13,324	107	21	37,968	304	387	26,328	211	294
CV-DMP 8	250	195,007	780	156	168,385	674	715	89,666	359	400
CV-DMP 9	1,000	26,678	27	5	81,258	81	92	58,441	58	69
COPD-DMP 1	2,508	154,504	62	12	214,239	85	90	-	-	-
COPD-DMP 2	1,600	93,909	59	12	49,751	31	38	47,422	30	36
COPD-DMP 3	133	49,639	373	75	55,191	415	493	53,016	399	477
COPD-DMP 4	2,400	44,586	19	4	32,599	14	18	24,464	10	15
DM-DMP 1	2,400	5,891	2	0	28,061	12	16	35,794	15	19
DM-DMP 2	233	162,889	699	140	387,879	1,655	1,709	-	-	-
DM-DMP 3	300	50,304	168	34	61,338	204	239	34,939	116	151
Heart failure - DMP	90	51,289	570	114	83,447	927	1,043	78,567	873	989
Stroke-DMP	75	46,374	618	124	21,004	280	419	13,846	185	324
Depression-DMP	150	184,114	1,227	245	105,744	705	774	153,477	1,023	1,093
Psychotic disorders-DMP	220	31,584	144	29	155,171	705	753	157,008	714	761
Eating disorders-DMP	220	7,223	33	7	102,207	465	512	94,812	431	478

*We used 5 years as amortization period; # These costs are not per patient; CV-DMP = cardiovascular disease management programme; COPD-DMP= Chronic Obstructive Pulmonary Disease disease management programme; DM-DMP= Diabetes Mellitus Disease Management Programme.

There is large variation in the total development and implementation costs of DMPs and in the development and implementation costs per patient. This variation is observed between and within a disease category. The variation can be explained by the large variability in DMP development duration, size of the DMP-providing organization and size of the target patient population. The DMP development duration was found to be positively related to the labour intensiveness during the development phase. The lengthier the development phase and the greater the number of (different) professionals involved, the higher the development costs. Considering that the development costs are highly positively correlated to the implementation costs, the length of the development phase is an important driver of total development and implementation costs.

7.2 Short-term costs

Note that the costs include all costs, not just the costs related to the particular disease. At baseline, patients in COPD-DMPs had the highest mean yearly outpatient hospital costs (€1,967), medication costs (€857), total healthcare costs (€4,368) and total costs (€5,320) while patients in CVR-DMPs had the highest mean yearly productivity loss (€1,648) (see Table 7.2). Patients in DM-DMPs had the highest primary care costs (€941). However, all differences between baseline and T1 follow-up were statistically insignificant and the standard deviations of the estimated means were large. As Table 7.2 shows, the changes across DMPs within the same disease and between diseases varied largely. Remarkably, the inpatient costs in all DM DMPs were reduced in contrast to some DMPs of the other diseases. Concerning all other costs, the changes ranged from negative to positive across DMPs.

Table 7.2 Costs per patient at baseline and differences between T0 and T1

	CVR			COPD			DM			Total sample	
	Mean at baseline (sd)	Mean Change (sd)	Range of change across DMPs	Mean at baseline (sd)	Mean Change (sd)	Range of change across DMPs	Mean at baseline (sd)	Mean Change (sd)	Range of change across DMPs	Mean change	Range of change across DMPs
Primary care	610 (857)	34 (1,069)	-510; +314	916 (1388)	49 (1,601)	-5; +155	941 (947)	-84 (1,226)	-236; +88	21 (1,273)	-510; +314
Outpatient hospital care	363 (769)	30 (954)	-443; +259	1,967 (13,256)	-119 (2,524)	-272; +22	354 (615)	115* (809)	+86; +169	-2* (1,583)	-443; +259
Inpatient hospital care$	587 (3,526)	624 (9,452)	-551; +2,148	659 (2,453)	320 (18,563)	-396; +1,162	701 (3,714)	-454 (4,065)	-1,211; -220	368 (12,426)	-1,211; +2,148
Medication	370 (362)	3 (261)	-45; +41	857 (601)	3 (417)	-2; +6	518 (482)	1 (318)	-44; +34	3 (323)	-45; +41
Total healthcare utilization costs	1,911 (4,102)	691 (9,812)	-1,107; +2,626	4,368 (14,256)	238 (19,080)	-672; +1,055	2,504 (4,015)	-446 (4,444)	-93; -1,066	382 (12,826)	-1,107; +2,626
Travelling	74 (215)	-2 (344)	-113; +90	226 (1,190)	-109 (1,145)	-328; +47	174 (378)	-22 (441)	-23; -19	-37** (699)	-328; +90
Productivity	1,648 (8,080)	-495 (7,349)	-1,988; +1,075	658 (4,724)	341 (6,603)	0; +459	216 (1,410)	188 (2,656)	-210; +454	-102 (6,571)	-1,988; +1,075
Total costs	3,302 (9,006)	468 (13,559)	-1,893; +4,269	5,320 (15,390)	85 (20,354)	-1,232; +375	3,489 (7,605)	-517 (9,662)	-1,591; -167	203 (15,448)	-1,893; +4,269

$ inpatient hospital care costs include also emergency care costs; * (p< 0.05); ** (p<0.01); the differences are calculated subtracting the costs at baseline from the costs at follow-up; primary care costs included contacts with GP, nurse practitioner, nurse, dietician, physiotherapist, podiatrist, lifestyle coach, etc. CV = cardiovascular; COPD= Chronic Obstructive Pulmonary Disease; DM= Diabetes Mellitus.

7.3 Long-term costs

When comparing T2 to T0 (Table 7.3), the changes across DMPs within the same disease and between diseases again varied largely. In the CVR DMPs the total healthcare costs as well as the total costs from a societal perspective increased. When averaged for all diseases, mean healthcare costs decreased slightly, as did the societal costs. Appendix Chapter 7 (1) gives these data for each DMP separately.

Table 7.3 Costs per patient at baseline and differences between T0 and T2

	CV			COPD			DM			Total sample	
	Mean at baseline (sd) [n]	Mean Change (sd)	Range of change across DMPs	Mean at baseline (sd) [n]	Mean Change (sd)	Range of change across DMPs	Mean at baseline (sd) [n]	Mean Change (sd)	Range of change across DMPs	Mean change	Range of change across DMPs
Primary care	604 (896)	45 1,150	-139; 175	902 (1,396)	34 (1,589)	-114; 261	973 (1,212)	-26 (1,570)	-196; 252	29 (1,382)	-196; 261
Outpatient hospital care	344 (616)	11 (978)	-200; 131	539 (1,039)	-46 (1,084)	-193; 25	350 (630)	81 (815)	34; 253	3 (991)	-200; 235
Inpatient hospital care$	705 (4389)	635 (11,084)	-820; 3,228	2,095 (13,748)	-1,113 (15,324)	-4,238; 1,184	588 (2,977)	207 (5,485)	-471; 1,481	-26 (12,106)	-4,238; 3,228
Medication	383 (367)	-100** (359)	-179; -62	856 (624)	-10 (473)	-108; 86	515 (523)	-103* (464)	-192; 65	-71** (418)	-192; 86
Total healthcare utilisation costs	2,016 (4,809)	595** (11,711)	-708; 3,254	4,349 (14,429)	-1,184 (15,490)	-4,088; 977	2,414 (3,431)	155 (6,231)	-364; 2,049	-79* (12,524)	-4,088; 3,254
Travelling	104 (759)	-71** (760)	-182; -3	209 (1,183)	-145* (1,156)	-317; -14	177 (398)	-101** (418)	-114; -51	-101** (878)	-317; -3
Productivity	1,727 (8,249)	-534 (8,990)	-8,674; 1,804	545 (4,096)	183 (7,265)	-854; 2,090	141 (915)	628 (5,578)	165; 2,136	-92 (7,931)	-8,674; 2,136
Total costs	3,539 (9,902)	167* (15,448)	-5,700; 3,619	5,330 (15,530)	-1,612 (17,075)	-5,336; 742	3,336 (7,609)	-244 (10,140)	-1,489; 1,998	-502** (15,340)	-5,336; 3,619

$ inpatient hospital care costs include also emergency care costs; * (p< 0.05); ** (p<0.01); the differences are calculated subtracting the costs at baseline from the costs at follow-up; primary care costs included contacts with GP, nurse practitioner, nurse, dietician, physiotherapist, podiatrist, lifestyle coach, etc. CV = cardiovascular; COPD= Chronic Obstructive Pulmonary Disease; DM= Diabetes Mellitus.

Table 7.4. presents the healthcare utilisation costs and the total costs (including travelling and productivity costs) per patient during the two-year follow-up period. Patients with COPD had clearly higher costs than patients in the other disease categories.

Table 7.4 Costs per patient during the two year follow-up

	Total healthcare utilisation costs		Total costs	
	mean	sd	mean	sd
CV (n=829)	4,008	12,986	5,756	16,446
COPD (n=464)	6,459	17,039	7,582	18,554
DM (n=241)	3,580	5,549	4,723	8,385
Total (n=1,534)	4,682	13,601	6,146	16,190

CV = cardiovascular; COPD= Chronic Obstructive Pulmonary Disease; DM= Diabetes Mellitus. SD = Standard Deviation.

Chapter 8: Cost-utility

8.1 Changes in utilities

The changes in EQ-5D utilities are presented in Table 8.1. During the 2-year follow-up, the mean EQ-5D utility was reduced.

Table 8.1 Long-Term Changes in Health-Related Quality of Life (EQ-5D)

	Baseline (T0; 2010)		Follow-up (T2; 2012)		Long-term change			
	M	SD	M	SD	M	SD	p^a	n
Onze Lieve Vrouwe Gasthuis (CV-DMP)	0.77	0.20	0.72	0.18	-0.045	0.12	0.005	51
De Stichting Eerstelijns Samenwerkingsverband Achterveld (CV-DMP)	0.88	0.12	0.87	0.14	-0.009	0.11	0.745	50
Regionale Organisatie Huisartsen Amsterdam (CV-DMP)	0.84	0.15	0.80	0.17	-0.046	0.15	0.004	33
De Stichting Gezondheidscentra Eindhoven (CV-DMP)	0.85	0.18	0.82	0.18	-0.028	0.09	0.036	62
Gezondheidscentrum Maarssenbroek (CV-DMP)	0.85	0.17	0.80	0.26	-0.046	0.23	0.252	47
Rijnstate (CV-DMP)	0.84	0.20	0.81	0.20	-0.023	0.17	0.062	139
Medisch Centrum Oud-West (CV-DMP)	0.84	0.17	0.78	0.31	-0.059	0.23	0.345	19
Universiteit Medisch Centrum St. Radboud (CV-DMP)	0.87	0.12	0.80	0.16	-0.068	0.13	0.016	23
Wijkgezondheidscentra Huizen (CV-DMP)	0.84	0.17	0.82	0.19	-0.023	0.17	0.163	93
HAFANK (Hartfalen Noord Kennemerland) (Heart failure DMP)	0.73	0.23	0.70	0.29	-0.026	0.14	1.000	10
Huisartsencoöperatie Midden-Brabant (COPD DMP)	0.70	0.25	0.71	0.25	0.004	0.24	0.518	90
Archiatros (COPD DMP)	0.81	0.18	0.78	0.21	-0.092	0.19	0.021	144
Stichting Gezond Monnickendam(COPD DMP)	0.82	0.23	0.76	0.25	-0.058	0.15	0.008	47
Zorggroep Almere (COPD DMP)	0.83	0.17	0.79	0.21	-0.035	0.18	0.220	61
Huisartsen Coöperatie Zeist (Diabetes DMP)	0.82	0.18	0.81	0.18	-0.010	0.17	0.491	96
Zorggroep Haaglanden (Diabetes DMP)	0.83	0.17	0.81	0.18	-0.019	0.247	0.410	23
Gezondheidscentrum De Roerdomp (Diabetes DMP)	0.80	0.24	0.79	0.19	-0.009	0.18	0.172	45
Chronische Ketenzorg Land van Cuijk en Noord Limburg BV (Co-morbidity DMP)	0.82	0.19	0.79	0.22	-0.029	0.20	0.125	137
Total within cardiovascular DMPs	0.84	0.18	0.81	0.20	-0.313	0.16	0.000	517
Total within COPD DMPs	0.79	0.21	0.76	0.23	-0.025	0.20	0.001	372
Total within Diabetes DMPs	0.82	0.20	0.81	0.18	-0.011	0.19	0.097	164
Total of all DMPs	0.82	0.19	0.79	0.21	-0.265	0.18	0.000	1170

Notes: M, mean; SD, standard deviation. [a]Paired Wilcoxon test, T0 *vs*. T2. Analyses included respondents who completed questionnaires at both T0 and T2.

8.2 Unadjusted cost utility analysis

The mean costs and QALYs of the most effective disease management programme and the least effective disease management programme are presented in Table 8.2. The incremental costs and incremental QALYs are not adjusted for the differences in the socio-demographic characteristics and quality of life of patients in the compared disease management programmes at baseline. Therefore, they should be interpreted with caution. The unadjusted ICERs from the healthcare perspective ranged from -32,257 (in the CV-secondary prevention sample) to 17,071 (in the CV both prevention sample).

Table 8.2 Results from the two-year cost-utility analysis (unadjusted)

	Most effective DMP *			Least effective DMP *			Incremental costs		Incremental QALYs	Unadjusted ICER	
	Costs HC	Costs SP	QALYs	Costs HC	Costs SP	QALYs	HC	SP		HC	SP
CV-primary [#]	2,593	4,098	1.19	2,644	5,412	1.13	-51	-1,314	0.06	-850	-21,900
	(2,621)	(7,898)	(0.46)	(5,523)	(11,685)	(0.50)					
CV-secondary [$]	4,786	5,682	1.07	2,528	4,524	1.14	2,258	1,158	-0.07	-32,257	-16,543
	(11,853)	(12,964)	(0.46)	(5,574)	(11,771)	(0.48)					
CV-both	5,051	6,572	1.14	2,149	3,605	0.97	2,902	2,967	0.17	17,071	17,453
	(15,189)	(20,037)	(0.49)	(9,802)	(13,665)	(0.38)					
COPD	6,809	7,815	1.02	5,199	6,236	1.25	1,610	1,579	-0.24	-6,851	-6,721
	(21,420)	(22,669)	(0.48)	(7,294)	(11,732)	(0.56)					
DM	3,406	3,611	1.04	3,217	4,654	1.24	189	-1,043	-0.20	-938	5,175
	(3,658)	(3,843)	(0.43)	(5,804)	(9,792)	(0.50)					

[#] primary prevention for CVD; [$] secondary prevention for CVD; CV = cardiovascular; COPD= Chronic Obstructive Pulmonary Disease; DM= Diabetes Mellitus. HC = Healthcare perspective; SP = Societal Perspective; ICER: incremental cost-effectiveness ratio; CE: cost-effective(ness); best is defined as most effective based on the Assessment of Chronic Illness Care instrument and worse as the least effective based on the same instrument.

8.3 Adjusted cost-utility analysis using propensity score matching: healthcare perspective

The results from the cost-utility analysis taking the healthcare perspective are presented in Table 8.3. These are the results after propensity score adjustment. This table shows that the most effective DMP for CVR-primary prevention led to statistically significant cost savings when compared to the least effective DMP in the same disease category (i.e. more than 95% of bootstrap replications in the southern quadrants). The most effective DMP targeting both CVR-primary and secondary prevention led to a significantly higher number of QALYs than the least effective DMP for these patients. Costs were also significantly higher (i.e. all bootstrap replication in the North East quadrant). The table also shows there is large variation in incremental costs (ranging from €-803 to €3,810) and incremental QALYs (ranging from -0.087 to 0.293) between the best and the worst DMP within a disease category. The 5000 bootstrapped ICERs plotted on the CE plane showed that there is large uncertainty around the estimated mean ICER. The cost-effectiveness planes are presented in Appendix Chapter 8 (1).

Table 8.3 Results from the two-year cost-utility analysis taking the healthcare perspective

	Most effective versus least effective DMP *	Incremental costs	Incremental QALYs	Mean ICER	% of 5000 simulated ICERs per quadrant in the CE plane			
					NW	NE	SW	SE
CV-primary [#]	4 VS 9	-803 (425)	-0.087 (0.115)	9,212	2	1	77	20
CV-secondary [$]	1 VS 3	1,918 (1,211)	0.024 (0.072)	79,445	34	60	3	3
CV-both	11 VS 5	3,810 (1,451)	0.293 (0.080)	13,012	0	100	0	0
COPD	12 VS 14	2,404 (3,015)	-0.098 (0.072)	-24,627	72	7	20	2
DM	18 VS 19	354 (699)	-0.307 (0.091)	-1,151	71	0	29	0

[#] primary prevention for CVD; [$] secondary prevention for CVD; CV = cardiovascular; COPD= Chronic Obstructive Pulmonary Disease; DM= Diabetes Mellitus. HC = Healthcare perspective; SP = Societal Perspective; CV = cardiovascular; COPD= Chronic Obstructive Pulmonary Disease; DM= Diabetes Mellitus. NE = North East; NW = North West; SW = South West; SE = South East. ICER: incremental cost-effectiveness ratio; CE: cost-effective(ness); best is defined as most effective based on the Assessment of Chronic Illness Care instrument and worse as the least effective based on the same instrument.

8.4 Societal perspective

From the societal perspective, the cost-utility results are similar to the results from the healthcare perspective except that for the primary CV prevention and diabetes samples the uncertainty about the incremental costs became larger (Table 8.4).

Table 8.4 Results from the two-year cost-utility analysis taking the societal perspective

	Most effective versus least effective DMP *	Incremental costs	Incremental QALYs	Mean ICER	% of 5000 simulated ICERs per quadrant in the CE plane			
					NW	NE	SW	SE
CV-primary [#]	4 VS 9	605 (2,603)	-0.087 (0.115)	-6,932	45	12	34	9
CV-secondary [$]	1 VS 3	2,514 (1,506)	0.024 (0.072)	104,130	35	60	2	3
CV-both	11 VS 5	4,887 (1,898)	0.293 (0.080)	16,691	0	100	0	0
COPD	12 VS 14	1,039 (3,556)	-0.098 (0.072)	-10,647	55	5	36	4
DM	18 VS 19	-1,355 (1,396)	-0.307 (0.091)	4,408	16	0	84	0

[#] primary prevention for CVD; [$] secondary prevention for CVD; CV = cardiovascular; COPD= Chronic Obstructive Pulmonary Disease; DM= Diabetes Mellitus. HC = Healthcare perspective; SP = Societal Perspective; CV = cardiovascular; COPD= Chronic Obstructive Pulmonary Disease; DM= Diabetes Mellitus. NE = North East; NW = North West; SW = South West; SE = South East. ICER: incremental cost-effectiveness ratio; CE: cost-effective(ness); best is defined as most effective based on the Assessment of Chronic Illness Care and worse as the least effective based on the same instrument.

8.5 Sensitivity analysis

Table 8.5 shows the results from the CUA from the healthcare perspective excluding the development and implementation costs. The most remarkable change in comparison to the main CUA (healthcare perspective) where 71% of the 5,000 bootstrapped ICERs regarding the DM DMPs was located on the North-West quadrant of the CE plane is that now 87% of the bootstrap

replications is located on the South-West quadrant. This change is a result from the higher development and implementation costs of the most effective disease management programme.

Table 8.5 Results from the two-year cost-utility analysis from the healthcare perspective excluding the development and implementation costs

	Best DMP VS worse DMP*	Incremental costs	Incremental QALYs	Mean ICER	% of 5000 simulated ICERs per quadrant in the CE plane			
					NW	NE	SW	SE
CV-primary [#]	4 VS 9	-302 (562)	-0.087 (0.115)	3,460	22	6	57	14
CV-secondary [$]	1 VS 3	1776 (1639)	0.024 (0.072)	73,549	31	56	6	7
CV-both	11 VS 5	3,730 (1,793)	0.293 (0.080)	12,741	0	100	0	0
COPD	12 VS 14	3,501 (3,797)	-0.098 (0.072)	-35,866	76	7	15	1
DM	18 VS 19	-1,906 (1,030)	-0.307 (0.091)	3,564	13	0	87	0

[#] primary prevention for CVD; [$] secondary prevention for CVD; CV = cardiovascular; COPD= Chronic Obstructive Pulmonary Disease; DM= Diabetes Mellitus. HC = Healthcare perspective; SP = Societal Perspective; CV = cardiovascular; COPD= Chronic Obstructive Pulmonary Disease; DM= Diabetes Mellitus. ICER: incremental cost-effectiveness ratio; CE: cost-effective(ness); best is defined as most effective based on the Assessment of Chronic Illness Care and worse as the least effective based on the same instrument.

Chapter 9: Explaining success of disease management programmes

While each of the projects was unique with regard to the diseases and populations addressed, implementation plans, healthcare professionals involved and site histories, there are features of the projects that may influence how well the goals laid out in their project proposals are (or are not) met. Crucial success factors include how project leaders organise the programmes, prior experience and preparation and the flexibility of both project leaders and healthcare professionals vis-à-vis the patient population and the development of the projects over time. Furthermore, interaction among professionals was found to be a crucial determinant of success of disease management programmes. We will discuss the sustainability and spread of disease management programmes to other settings, as well as the explanations for better experiences among patients with chronic care delivery.

9.1 Preparation

Organisation is a key feature in the implementation of project plans. Many of the project sites hired project leaders or assigned project leadership duties to an experienced clinician. Project leaders (or leadership teams, managers and clinical experts) organised the work of the programmes, oversaw the development of care protocols, transmitted this information to healthcare professionals, supported healthcare professionals in the changes needed, responded to the requests from health insurance companies and coordinated the efforts of outside vendors (such as software developers). They are typical 'hybrid managers' in that they connect a multitude of factors and actors to make programmes work. Project leaders organised this work in various ways, such as protocol books or computer files. Organisation activities allowed the project leadership team to effectively work with the various actors involved in the projects to develop and implement the disease management programmes. Crucially, project leaders are able to connect the different 'worlds' of the projects through their organisation efforts—patients, professionals as well as a diversity of technical, social and financial contexts.

The project sites came into the research study with various backgrounds and levels or types of experience with disease management. Being prepared for the disease management program before it started (whether through development of concrete plans before the project start date or through building on previously developed programmes) saved project leaders time and effort at the start of the disease management programmes. It is important to note that complete implementation of disease management takes much preparation. In cases where this preparation was done prior to or early in the project timeline, projects were able to implement aspects of the disease management programmes faster, tailor the programmes to the needs of healthcare professionals and patients earlier and reflect sooner on the programmes. Fully understanding the goals of the program, establishing relationships with potential partners and exploring prospective features of the program during the proposal development phase have the potential to speed the development of the programmes. Building in preparation time in the timeline is another crucial factor getting interventions implemented faster.

9.2 Flexibility

Meeting project goals often requires adaptation and flexibility on the part of project leaders and healthcare professionals. This can be seen in Ursula, where the project leader responds to the needs

of the young women by adding features to the website, in Zeist, where the project leader worked with (and through) challenges in the development of an electronic medical record system and in Radboud, where the project leader adapted aspects of the program based on the feedback from healthcare professionals. This flexibility is also evident where certain aspects of the disease management programme are changed or discontinued. While the project leaders and healthcare professionals in Zeist developed and implemented patient education classes, the classes were not popular; the project team stopped offering classes, but continued to work as a multidisciplinary care team to meet the needs of patients. The flexibility of the project leaders and healthcare professionals points to the needs for reflection on the needs of the patients and healthcare professionals and allows for changes during the development and implementation phases of the disease management programmes. This reflection helps practices translate goals on paper into concrete actions that better align with the needs of patients and professionals in practice and is therefore also a crucial aspect for success of disease management programmes.

9.3 Interaction among professionals

Well-functioning teams comprising professionals from diverse backgrounds are at the core of disease management programmes that use the chronic care model. Jody Hoffer Gittell (2006) has demonstrated that relational coordination with the aim of task integration is a major predictor of quality of care. Good communication among team members is required and professionals must have the same goals, share knowledge with each other and mutually respect one another. Our study showed that disease management programmes not only led to improved quality of care but such implementation improves relational coordination and functioning among professionals from various disciplines within the program. Furthermore, we saw that improved relational coordination predicted improved quality of chronic care delivery. These observations suggest that diverse healthcare professionals must be strongly connected for disease management programmes to provide effective, holistic care that embraces all facets of the chronic care model (Cramm and Nieboer 2012a).

9.4 Sustainability

Several (systematic) reviews on the sustainability of quality improvement programmes have documented the fragmented and underdeveloped nature of the sustainability literature due to limited funding for monitoring programmes after initial implementation (Buchanan et al. 2005; Greenhalgh et al. 2004; Wiltsey Stirman et al. 2012). There is a general lack of empirical evidence on sustainability of programmes that improve the quality of care delivery over time (Bowman et al. 2008; Wiltsey Stirman et al. 2012). Therefore, we aimed to identify the predictive role of short and long term improvements in quality of chronic care delivery on the sustainability of programmes. Our study demonstrated that effectively improving the quality of care delivery during both the first and second year after program implementation predicted the sustainability of these programmes. Effectively improving the quality of care delivery has been identified to primarily depend on system changes (Berwick 2003; Shojania and Grimshaw 2005). This may also explain the long-term success of the disease management programmes to improve quality of care delivery which involves system changes in care delivery compared to quality improvement programmes not incorporating such system changes (Cramm and Nieboer 2013b).

9.5 Spread to other settings

In 2012 we asked professionals about the dissemination of work practices within the disease management programme to other settings (Table 9.1).

Table 9.1 Spread of the disease management programme

Spread of the disease management programme	Percentage (strongly) agree
Professionals in other settings also use the guidelines/protocols/manuals from the disease management programme	52%
The required skills for the disease management programme have also been trained in other settings	46%
By now, they also use the new work-method of the disease management programme in other settings	60%
Professionals in other settings have been instructed how to use the materials for the disease management programme	54%
Professionals in other settings now also use the same, new materials for the disease management programmes	47%

These results show that work practices of the disease management programme are successfully being spread to other settings. Over half of the respondents (60%) report that the new disease management method is being used in other settings, 54% report that professionals in other settings have been instructed how to use the materials for the disease management programme, 52% of the respondents say that professionals in other settings also use the guidelines/protocols/manuals from the disease management programme, 47% report that professionals in other settings now also use the same, newly developed materials for the disease management programmes and 46% say that the required skills for the disease management programme have also been trained in other settings.

9.6 Patients' experiences

Both the quality of care and changes in chronic care delivery predicted more positive experiences with care delivery among chronically ill patients (Cramm and Nieboer 2013a). While overall quality of care delivery improved, the heart failure, co morbidity and Monnickendam COPD disease management programmes were not able to improve the quality of care delivery, although their decrease is not significant. It may be more difficult to achieve such positive results with disease management programmes that target patients with severe conditions, such as heart failure, COPD (GOLD 3–4) and co morbidity (Cramm and Nieboer 2013a). Patients' experiences with chronic care delivery are better when disease management programmes implement all six dimensions of the chronic care model. Overall, these practice projects have led to important changes in care for chronically ill patients with regard to the organisation of care (including the transfer of tasks from physicians to nurses and the shift from secondary to primary care), decision-making support (through protocols, standards of care and education), information and communications technology [implementation of a chain information system (KIS) with or without a patient portal] and self-

management support (through reflective discussion and motivational interviews). These structural improvements in the quality of care will have increasing effects over time.

Chapter 10: Discussion and conclusions

The aim of this study was to evaluate a range of disease-management projects by capturing them in a common conceptual framework and by using similar structure, process and outcome measures. This study was guided by 6 research questions which we will answer in this chapter.

1) Can we develop and apply a common framework to describe and compare the components of each disease management programme and each patient population?

We used the chronic care model to evaluate disease management programmes in the Netherlands. This model provides an organised multidisciplinary approach to the delivery of care for patients with chronic diseases, which involves the community and the healthcare system and fosters communication between healthcare professionals and well-informed patients. Disease management programmes are aimed at patients as well as professionals.

The chronic care model clusters six interrelated components of healthcare systems: healthcare organisation, community linkages, self-management support, delivery system design, decision support and clinical information systems. The idea is to transform chronic disease care from acute and reactive to proactive, planned and population-based (Wagner et al. 2001). Of the six components, the self-management component relies heavily on community-based resources, including rehabilitation programmes, patient education materials, group classes and ideally a home health case manager who can regularly assess difficulties and acknowledge accomplishments. The delivery-system design component of the chronic care model requires well-trained clinical teams that ensure successful self-management, coordinate preventive care, screen for common co morbidities and address questions or acute issues around the clock. An active clinical information system provides healthcare professionals with performance feedback and automated reminders of practice guidelines. Finally, the decision support component involves the use of evidence-based practice guidelines, which are critical for the optimal management of any chronic illness. Effective management of complex chronic diseases is best accomplished by collaboration among healthcare professionals with the support of a variety of healthcare resources. The Assessment of Chronic Illness Care-Short version (ACIC) (Bonomi et al. 2002) and the Assessment of Chronic Illness Care-Short version (ACIC-S) (Cramm et al. 2011) are both based on six areas of system change suggested by the chronic care model and were developed to help disease-management teams identify areas for improvement in chronic illness care and evaluate the level and nature of improvements made in their system. The ACIC(-S) is one of the first comprehensive tools targeting generic organisation of chronic care across disease populations, rather than traditional disease-specific tools such as HbA1c levels, productivity measures (e.g., number of patients seen), or process indicators (e.g., percentage of diabetic patients receiving foot exams). The ACIC(-S) attempts to represent poor to optimal organisation and support of care in the chronic care model areas.

Research shows that the ACIC(-S) appears sensitive to interventions across chronic illnesses and helps teams focus their efforts on adopting evidence-based chronic care changes. As such the ACIC(-S) represents a useful tool to investigate the progress of disease management programmes over time. Therefore, we used the ACIC(-S) to investigate professionals' assessment of chronic care delivery (Cramm et al. 2011). In addition, we used this model to develop a framework and map all

interventions implemented within the 22 disease management programmes to increase our understanding of what actually is being done in each disease management programme.

We found that the chronic care model represents a common framework that can be used to describe and compare the components of each disease management programme and is applicable to each patient population. We did find that all 22 disease management programmes designed and implemented interventions based on the chronic care model in theory but that they all used their own unique way of providing disease management. To evaluate cost-effectiveness of disease management programmes a methodological framework to facilitate the application of Multi-Criteria Decision Analysis (MCDA) in a broader economic evaluation of disease management programmes including the most relevant outcomes and cost categories is advisable (Tsiachristas et al. 2013). We developed a framework for the application of MCDA in the economic evaluation of disease management programmes. The framework (see Appendix Chapter 10 (1)) distinguishes between the development phase of disease management programmes and the implementation phase. In the development phase, a mixture of patient-directed (e.g. self-management training), professional-directed (e.g. education and training) and organisational interventions (e.g. electronic patient records) are usually selected, designed and prepared to be implemented. The development costs accumulated in this phase are also incorporated in our framework.

2) What are the effects of disease management interventions on the primary outcomes at the patient, professional and organisational level?

Patient outcomes

Looking at differences between patient populations we see that about half of the respondents are female. One exception is the population of patients with eating disorders; 96% of these patients are female. At baseline, COPD patients report having lower educational levels and smoke more often compared to patients with other chronic diseases. Heart failure patients report the lowest physical quality of life followed by COPD patients. Patients with eating disorders and psychotic disorders report the lowest mental quality of life compared to other chronically ill patients.

Overall, short-term effects of the disease management programmes showed that physical activity improved and the percentage of smokers decreased significantly over time (Cramm et al., 2014), whereas physical and mental quality of life declined in the short run. Changes in health behaviours and quality of life did not vary between patients with or without co morbidity. There is evidence from large long-term randomised controlled trials that quality of life of chronically ill patients slowly deteriorates over time, especially in the placebo groups but sometimes also in the intervention groups (Tashkin et al. 2008; Calverley et al. 2007). Although physical quality of life also deteriorated among patients in our study, we expected that improvements in health behaviour (physical activity and smoking) will prevent or slow down the deterioration of physical quality of life normally seen in a chronically ill population (Cramm et al., 2014). Our qualitative research indicated that many of the aspects of disease management programmes targeted at improving health behaviour are expected to have a longer-term impact on quality of life. A meta-analysis of interventions based on the chronic care model to improve care for chronic illnesses after a one-year time frame found that the evidence on quality of life outcomes was mixed (Tsai et al. 2005).

Looking at the long-term benefits of disease management programmes in the Netherlands on primary outcomes for patients we can conclude that they have successfully improved health behaviours and physical quality of life of chronically ill patients. These findings are in line with those of Hung and colleagues (2007), who found that interventions based on the chronic care model offer a useful framework for preventive purposes by addressing important risky health behaviours. Changes in health behaviours and mental quality of life did not vary between patients with or without co morbidity. Long term changes in physical quality of life did vary significantly; greater improvements were found in patients with co morbidity. Physical quality of life of co morbidity patients was, however, much lower at baseline than those without co morbidity. After two years of participating in the disease management programme this gap in physical quality of life became smaller. We also investigated effectiveness of disease management programmes in clinical outcomes based on data registries collected by the disease management programmes. These results showed positive effects on clinical outcomes of patients. Looking at the long-term benefits of disease management programmes on physical quality of life we can conclude that they were indeed successful in improving quality of life in the long run. While we found a decrease in physical quality of life after a one-year time frame these results show that physical quality of life did improve after a two-years time frame. This supports our expectation that improvements in health behaviour (physical activity and smoking) and other aspects of disease management programmes have a longer-term impact on quality of life. Looking at the long-term benefits of disease management programmes on broader quality of life we can conclude that they were unsuccessful in improving or even maintaining chronically ill patients' mental quality of life. Overall, mental quality of life of chronically ill patients decreased over-time. An important implication is therefore to focus on broader self-management abilities and overall quality of life, not physical functioning, disease limitations and lifestyle behaviours only (Nieboer, 2013). A challenge is to implement interventions that fit the needs of patients and that stimulate and enhance mental quality of life.

In 2013, we also investigated health behaviours and quality of life among a selection of all the 22 disease management programmes to see if they were able to sustain their improvements. Overall, these results show that these disease management programmes were able to sustain improvement in patients' physical activities, quit current smokers and physical quality of life, but not in mental quality of life.

Quality of care delivery

Regarding outcomes at the professional and organisational level we clearly saw that implementation of disease management programmes led to a significant improvement in all areas of the chronic care model and all aspects of relational coordination (quality of communication and coordination) among professionals from various disciplines. Our findings show that disease management programmes, as implemented in the Netherlands, can improve the quality of delivery of chronic care (Cramm and Nieboer 2013a; Cramm and Nieboer 2012a). They also show that improved relational coordination can predict improved quality of chronic care delivery. These observations suggest that diverse healthcare professionals must be strongly connected for disease management programmes to provide effective, holistic care that embraces all facets of the chronic care model. These findings underscore the dynamic and interdependent relationship between relational coordination and the quality of chronic care delivery, which has important implications for disease management

programmes. Potential collaborators who implement professional and organisational interventions, such as continuing education and communication systems, respectively, support effective collaboration among diverse professionals. Training professionals in relational competence — a process that is built into the chronic care model and can be incorporated into any chronic disease management programme — increases their ability to visualise the larger process and recognise their interconnectedness in accomplishing their shared goal. In this case, that goal is to broadly support the needs of chronically ill patients. Such competence also makes them better able to see other professionals' perspectives, empathise with their situations and respect their work, even if that work requires lesser skills or is of lower status (Cramm and Nieboer 2012a).

Our findings also showed that both the quality of care and changes in chronic care delivery predicted more positive experiences of chronically ill patients. Some differences, however, stand out. The heart failure, co morbidity and Monnickendam COPD disease management programmes were not able to improve the quality of care delivery (Cramm and Nieboer 2013b). Previous meta-analyses and reviews have also reported heterogeneity in the effectiveness of disease management programmes for patients with COPD and heart failure that they ascribed to several factors such as differences in study quality and the length of follow-up (Drewes et al. 2012; Elissen et al. 2012; Lemmens et al. 2011); however, the 17 disease management programmes in our study had the same length of follow-up and were assessed using the same study design. Mackenzie and colleagues (1996) additionally identified a negative relationship between the severity of chronic diseases and quality of care, which may explain why these disease management programmes were not able to improve quality of care. These three disease management programmes included patients with greater disease severity, namely patients with heart failure, co morbidity and severe COPD. The health condition of patients with heart failure is known to decline rapidly (Burton et al. 2012) and this disease management programme had the largest attrition rate due to death among the Dutch disease management programmes examined here (13 vs. less than 1% in the other disease management programmes that was reported back to us). Providing high-quality care for such a highly burdened patient population in the primary care setting may be difficult and more intensified care may be needed. The same argument may apply to the co morbidity disease management programme; delivering high-quality care to patients with multiple chronic conditions may be difficult due to their complex needs. Lastly, one of the four COPD disease management programmes examined in this study did not improve the quality of care; this programme included COPD patients with Global Initiative for Obstructive Lung Disease (GOLD) stages 1–4 (classification of pulmonary function: 1 = mild, 2 = moderate, 3 = severe, 4 = very severe), whereas the other three programmes included only COPD patients with GOLD stages 1 and 2. Thus, including patients with more severe COPD may explain why this disease management programme was not able to improve quality of care. Disease management programmes may find it more difficult to enhance the quality of care for patients with more severe diseases as the diseases progress and the patients' health status deteriorates. These patients may require a case-management type of care or an intensified disease management programme (Cramm and Nieboer 2013b).

3) What interventions are actually performed within the context of the 'disease management in chronic diseases' programme?

A summary of interventions implemented within the 22 disease management programmes is provided in Chapter 4 (Table on pages 23 and 24). Less used interventions (in < 20% of the 22

disease management programmes) were: communication platform between stakeholder about patients, hosting a health market, support of self-management using the internet, email or sms, e-consultation, tele-monitoring, reflection meetings, cognitive behavioural therapy, use of care protocols for immigrants, specific plan for immigrant population, joint consultation hours and use of Electronic Patient Records system with Patient Portal. Most used interventions (in > 80% of the 22 disease management programmes) were: cooperation with external community partners, treatment and care pathways in out- and inpatient care, promotion of disease specific information, life-style interventions, personal coaching, motivational interviewing, use of care standards / clinical guidelines, training and independence of practise assistants, professional education and training for care providers, automatic measurement of process/outcome indicators, delegation of care from specialist to nurse/care practitioner, meetings of different disciplines for exchanging information and Hospital or Practice Information System. Community interventions were implemented less often under the disease management programmes, which may explain why this dimension did not improve the first year. It is also notable that self-management support is rather narrowly focused to manage one's chronic condition. This may explain why patients' physical quality of and health behaviours improved. At the same time we saw that mental quality of life weakened as a consequence of living with a chronic condition and possible deterioration of functional capacity (social, cognitive and physical). Thus, these disease management programmes did not succeed in sustaining mental quality of life, let alone improving them. So the question is whether these disease management programmes should be labelled successful – given that they improved health behaviour and physical quality of life in the patient populations involved – or not fully successful, as they failed to stop the worsening of mental quality of life. In all likelihood, the truth lies midway between the two. It would seem important, though, to achieve a shift to a broader view of disease management, encompassing more than merely management of a chronic condition (Nieboer 2013).

4) What are the total costs (including implementation costs and all downstream healthcare costs) associated with the interventions and how are they financed and reimbursed?

Concerning the development and implementation costs of DMPs, there is wide variation which is driven primarily by the duration of the development phase and the number of (different) professionals involved. Both cost drivers probably depend on the level of integrated care that was already present before starting the development of a DMP. In other words, DMPs that had to be set up from scratch had longer development duration and required more manpower.

COPD patients had the highest healthcare costs at baseline, followed by patients with diabetes and patients with elevated cardiovascular risk. Hospitalization costs were the main cost driver of healthcare utilization costs in the CVR and COPD samples, followed by the primary care costs. This order is reversed in the diabetes sample were primary care costs were the main cost driver.

 The healthcare utilization costs did not change during the first year of follow-up. However, during the second year of follow-up we observed a slight reduction in costs of healthcare utilization. There are no indications of substitution of secondary by primary care. If there is substitution, it did not lead to a reduction in total cost per patient. It might be interesting to investigate substitution in more detail by testing if there is a reduction in hospital admission on the pulmonary ward for the COPD DMPs, on the cardiology ward for the CVR DMPs, on the neurology ward (for stroke DMP), on the internal medicine ward for DM DMP. This will be done in future, more detailed, analyses.

The financing of care delivered by DMPs changed during the follow-up period. At baseline there were no CVR and COPD DMPs with care contracted via bundled payments. This changed during the follow-up period where 22% of the CVR-DMPs and 75% of the COPD-DMPs had bundled payment contracts. This is certainly a positive development considering that bundled payment facilitates the successful implementation of DMPs (Tsiachristas et al., 2011, Tsiachristas et al., 2013).

5) How do these costs relate to the effects described under (2)?

When comparing the most effective DMP for primary prevention of CVR with the least effective DMP within the same category, there were significant savings in healthcare costs, but no difference in QALYs. When comparing the most effective with the least effective DMP targeting both primary and secondary prevention of CVR there were significant QALY gains at an increase in healthcare costs, resulting in a cost-effectiveness ratio of €13,000 per QALY gained. The cost-effectiveness ratios of the most versus the least effective DMP for COPD and diabetes was negative due to higher costs but no QALY gains. Hence, the cost-effectiveness of DMPs varied considerably, most likely depending on the components of the program, the target population, the success of the implementation and the costs of managing and operating the program. These are all factors that contractors of DMPs should consider in the negotiation phase.

6) What are crucial success and failure factors that influence the effect of disease-management interventions, what determines sustainability and how is this spread to other settings?

The qualitative research explores the realities of disease management in practice, analysing how the implementation of disease management programmes can also (re-)shape care delivery, expectations of healthcare professionals and patients and the respective roles of healthcare professionals, patients and project leaders. This research has found that organisation, preparation and flexibility are needed for the successful implementation of disease management programmes.

Our study also demonstrated that effectively improving the quality of care delivery during both the first and second year after programme implementation predicted the sustainability of these programmes (Cramm and Nieboer 2013a). These findings are interesting, especially in light of the persistence of major problems in the sustainability of quality improvement in other programmes with the same aim (Berwick 2005; Institute of Medicine 2006; Leatherman and Sutherland 2004; McGlynn et al. 2003; Schoen et al. 2006; Seddon et al. 2001). Various reasons have been identified for these problems, such as organisational structures that block the improvement of care delivery and resistance to change old working methods among professionals (Grol and Grimshaw 2003; Grol, Wensing and Eccles 2005; Institute of Medicine 2006; Rosenberg 2003). Effectively improving the quality of care delivery had been identified to primarily depend on system changes (Berwick 2003; Shojania and Grimshaw 2005). This may also explain the long-term success of disease management programmes to improve quality of care delivery which involves system changes in care delivery compared to quality improvement programmes not incorporating such system changes. Changing systems of care delivery alone is not enough, however. It does not automatically result in changing old working methods of professionals and successfully sustain the new working method (Wiltsey Stirman et al. 2012). We expected that successfully improving quality of care delivery by newly implemented disease management programmes would positively affect sustainability of these programmes. This research confirmed our expectations and clearly showed that both short and long

term improvements in quality of chronic care delivery predicted programme sustainability. This study showed that increased organisational support and system implementation leads to changes in behaviour of professionals. The ability of professionals to effectively improve quality of chronic care delivery as a result of the disease management approach is expected to have positively influenced professionals' views on this approach making them more motivated to change their old ways and making the new working method part of their daily routine practice. Unsuccessfully improving quality of care delivery may have resulted in preference for old working habits, with the danger of discontinuation of the new working method within the disease management approach by professionals (Cramm and Nieboer 2013a). Furthermore, results show that work practices of the disease management programme are successfully being spread to other settings. Over half of the respondents (60%) report that the new disease management method is being used in other settings, 54% report that professionals in other settings have been instructed how to use the materials for the disease management programme, 52% of the respondents say that professionals in other settings also use the guidelines/protocols/manuals from the disease management programme, 47% report that professionals in other settings now also use the same, new materials for the disease management programmes and 46% say that the required skills for the disease management programme have also been trained in other settings.

Limitations

The study has several limitations. First and most importantly, this study did not include control groups corresponding to all the different patient groups. Therefore, we were unable to determine whether improvements in the quality of care delivery, health behaviours and physical quality of life were caused by the disease management programmes or other factors. Secondly, because this study included patients enrolled in disease management programmes, our findings apply only to similar disease management programmes and not, for example, to commercialised disease management programmes. Thirdly, small numbers of patients participated in some disease management programmes and the results should thus be interpreted with caution. Fourthly, we found differences between respondents who completed T0 questionnaires only vs. those who also completed follow-up questionnaires (T0 and T1 or T0 and T2) regarding their age, mental quality of life and educational level. Furthermore, respondents who completed questionnaires at T0 and follow-up were on average more physically active than were those who completed only one questionnaire, which may have resulted in non-response bias. Physical activity may also be higher compared to patients not responding at all, which limits generalisability of our study findings.

Overall, we can conclude that quality of chronic care delivery substantially improved. Of great importance in the care process is the role of the patients themselves. This is why the disease management programmes all place a focus on self-management. Interventions aimed at self-management include lifestyle counselling, smoking cessation and exercise programmes and active involvement in drawing up a personal treatment plan. The effect was a lower percentage of smokers and more intense exercise after implementation of the disease management programme. In addition, patients' physical quality of life improved on the longer term. On the other hand, mental quality of life declined both on the short and long term. Seeing that the self-management interventions notably were targeted to life style and physical quality of life, it would be worthwhile

also to pay more attention in the future to the mental quality of life aspects of having to live with a chronic condition.

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2. Cramm, J.M., Nieboer, A.P. (2014). Short and long term improvements in quality of chronic care delivery predict program sustainability. *Social Science and Medicine*. 101:148-154.

3. Cramm, J.M., Nieboer, A.P. (2013). High-quality chronic care delivery improves experiences of chronically ill patients receiving care. *International Journal for Quality in Healthcare*. 25(6):689–695.

4. Cramm, J.M., Tsiachristas, A., Hipple-Walters, B., Adams, S., Bal, R., Huijsman, R ., Rutten-Van Mölken, M.P.M.H., Nieboer, A.P. (2013). The management of cardiovascular disease in the Netherlands: analysis of different programmes. *International Journal for Integrated Care*. 13:e028.

5. Cramm, J.M., Nieboer, A.P. (2014). The effects of social and physical functioning and self-management abilities on well-being among patients with cardiovascular diseases, chronic obstructive pulmonary disease, and diabetes. *Applied Research in Quality of Life*. 9(1) 113-121.

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9. Cramm, J.M., Nieboer, A.P. (2012). The Chronic Care Model: congruency and predictors among patients with cardiovascular diseases and Chronic Obstructive Pulmonary Disease in the Netherlands. *BMC Health Services Research.* 12:242.

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12. Cramm, J.M., Nieboer, A.P. (2012). Self-management abilities predict physical health and depressive symptoms among patients with cardiovascular diseases, chronic obstructive pulmonary disease, and diabetes. *Patient Education and Counseling*. 87(3):411-415.

13. Cramm, J.M., Strating, M.M.H., Vreede, P.L. de, Steverink, N., Nieboer, A.P. (2012). Validation of the Self-Management Ability Scale (SMAS) and development and validation of a shorter scale (SMAS-S) among older patients shortly after hospitalisation. *Health and Quality of Life Outcomes*. 10:9.

14. Cramm, J.M., Nieboer, A.P. (2012). Disease-management partnership functioning, synergy, and effectiveness in delivering chronic-illness care. *International Journal for Quality in Health Care*. 24(3):279-285.

15. Cramm, J.M., Nieboer, A.P. (2012). Relational coordination promotes quality of chronic-care delivery in Dutch disease-management programs. *Health Care Management Review*. 37(4):301-9.

16. Tsiachristas, A., Hipple-Walters, B., Lemmens, K.M.M., Nieboer, A.P., Rutten-Van Mölken, M.P.M.H. (2011). Towards integrated care for chronic conditions: Dutch policy developments to overcome the (financial) barriers. *Health Policy*. 101(2):122-132.

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Appendix Chapter 3

1: Response rates patient surveys

	Baseline (T0; 2010)		Follow-up (T1; 2011)		Follow-up (T2; 2012)		Follow-up (T3; 2013)	
	Sent n	response %	Sent n	response %	Sent n	response %	Sent n	response %
Onze Lieve Vrouwe Gasthuis (CV-DMP)	369	37%	369	33%	322	25%	301	19%
De Stichting Eerstelijns Samenwerkingsverband Achterveld (CV-DMP)	200	57%	134	65%	107	65%	-	-
Regionale Organisatie Huisartsen Amsterdam (CV-DMP)	320	35%	275	32%	175	28%	-	-
De Stichting Gezondheidscentra Eindhoven (CV-DMP)	300	47%	285	42%	269	36%	-	-
Gezondheidscentrum Maarssenbroek (CV-DMP)	653	48%	426	48%	392	30%	372	26%
Rijnstate (CV-DMP)	400	71%	360	68%	338	58%	-	-
Medisch Centrum Oud-West (CV-DMP)	100	40%	71	35%	71	42%	-	-
Universiteit Medisch Centrum St. Radboud (CV-DMP)	250	52%	250	33%	180	27%	-	-
Wijkgezondheidscentra Huizen (CV-DMP)	495	32%	440	42%	397	39%	-	-
HAFANK (Hartfalen Noord Kennemerland) (Heart failure DMP)	54	80%	49	73%	48	35%	-	-
Huisartsencoöperatie Midden-Brabant (COPD DMP)	291	47%	389	54%	368	51%	365	47%
Archiatros (COPD DMP)	600	66%	522	67%	503	45%	354	49%
Stichting Gezond Monnickendam (COPD DMP)	133	67%	125	62%	117	55%	102	62%
Zorggroep Almere (COPD DMP)	130	59%	69	67%	67	83%	-	-
Huisartsen Coöperatie Zeist (Diabetes DMP)	278	77%	221	52%	204	56%	180	56%
Zorggroep Haaglanden (Diabetes DMP)	165	62%	119	46%	50	42%	-	-
Gezondheidscentrum De Roerdomp (Diabetes DMP)	280	39%	259	34%	220	41%	-	-
Chronische Ketenzorg Land van Cuijk en Noord Limburg BV (Co morbidity DMP)	341	43%	339	45%	306	48%	273	46%
Sint Lucas Andreas (Stroke DMP)	112	45%	130	33%	130	29%	130	23%
De Stichting Gezondheidscentra Eindhoven (Depression DMP)	60	22%	-	-	-	-	-	-
Van Arkel (Psychotic disorders DMP)	165	24%	165	27%	165	26%	-	-
Usrula (Eating disorders DMP)	261	45%	261	46%	217	46%	-	-
Total of all DMPs	**5957**	**50%**	**5258**	**47%**	**4646**	**42%**	**2077**	**38%**

Notes: DMP, Disease Management Programme.

2: Interviews conducted at in-depth qualitative case sites

Site	Interviews
Land van Cuijk	8
Ursula	16
Zeist	17 (including 7 patient interviews)
Tilburg	9
Radboud (Nijmegen)	6
Total	*56*

2: A sample interview guide for clinicians and project leaders is below:

1. Why was the program developed?
2. How does your project fit into the care standard?
3. What is the need for the program?
4. What does it mean to treat …?
5. What are the barriers to implementation?
6. How does communication happen?
7. What has feedback been to the implementation from staff?
8. How has your team helped in the creation and implementation of the project?
9. How was your team developed?
10. What has patient feedback been?
11. What has clinician feedback been?
12. What does it mean to have a disease management system or project?
13. What does self-management mean?
14. What good surprises have you had?
15. What are you proud of?

Appendix Chapter 6

1: Short-Term Changes in Physical Activity within each disease management programme

	Baseline (T0; 2010)		Follow-up (T1; 2011)		Short-term change			
	M	SD	M	SD	M	SD	p^a	n
Onze Lieve Vrouwe Gasthuis (CV-DMP)	4.91	(2.18)	5.09	(1.90)	+0.17	(2.37)	0.625	47
De Stichting Eerstelijns Samenwerkingsverband Achterveld (CV-DMP)	5.64	(1.61)	5.40	(1.74)	-0.23	(1.74)	0.360	47
Regionale Organisatie Huisartsen Amsterdam (CV-DMP)	5.38	(2.02)	5.45	(1.85)	+0.06	(1.84)	0.813	47
De Stichting Gezondheidscentra Eindhoven (CV-DMP)	5.03	(1.91)	5.60	(1.66)	+0.57)	(1.98)	0.028	62
Gezondheidscentrum Maarssenbroek (CV-DMP)	4.95	(2.02)	5.39	(1.89)	+0.44	(2.39)	0.076	96
Rijnstate (CV-DMP)	4.55	(2.28)	5.36	(1.75)	+0.82	(2.25)	<0.001	119
Medisch Centrum Oud-West (CV-DMP)	6.13	(1.69)	6.00	(1.07)	-0.13	(1.73)	0.769	15
Universiteit Medisch Centrum St. Radboud (CV-DMP)	5.28	(1.99)	5.07	(2.12)	-0.21	(1.91)	0.479	43
Wijkgezondheidscentra Huizen (CV-DMP)	4.73	(2.16)	4.98	(2.11)	+0.25	(2.14)	0.365	59
HAFANK (Hartfalen Noord Kennemerland) (Heart failure DMP)	5.30	(2.21)	5.20	(2.30)	-0.10	(2.47)	0.901	10
Huisartsencoöperatie Midden-Brabant (COPD DMP)	4.82	(2.03)	4.70	(2.19)	-0.11	(1.20)	0.631	71
Archiatros (COPD DMP)	4.85	(2.08)	5.12	(2.13)	+0.27	(2.11)	0.129	146
Stichting Gezond Monnickendam (COPD DMP)	4.08	(2.51)	5.44	(2.09)	+1.36	(2.72)	0.005	36
Zorggroep Almere (COPD DMP)	5.27	(2.05)	5.88	(1.21)	+0.61	(2.16)	0.050	51
Huisartsen Coöperatie Zeist (Diabetes DMP)	5.20	(1.77)	5.25	(1.77)	+0.05	(2.01)	0.825	81
Zorggroep Haaglanden (Diabetes DMP)	4.22	(2.12)	5.11	(1.66)	+0.89	(2.40)	0.030	37
Gezondheidscentrum De Roerdomp (Diabetes DMP)	4.25	(1.90)	4.47	(2.13)	+0.22	(1.40)	0.346	36
Chronische Ketenzorg Land van Cuijk en Noord Limburg BV (Co morbidity DMP)	5.15	(1.97)	5.25	(1.90)	+0.10	(1.81)	0.630	84

Notes: M, mean; SD, standard deviation. [a]Paired *t*-test, T0 *vs*. T1. Analyses included respondents who completed questionnaires at both T0 and T1.

2: Short-Term Changes in Smoking within each disease management programme

	Baseline (T0; 2010)	Follow-up (T1; 2011)		
	%	%	p^{a}	n
Onze Lieve Vrouwe Gasthuis (CV-DMP)	30	23	0.063	74
De Stichting Eerstelijns Samenwerkingsverband Achterveld (CV-DMP)	14	12	1.000	59
Regionale Organisatie Huisartsen Amsterdam (CV-DMP)	27	20	0.125	56
De Stichting Gezondheidscentra Eindhoven (CV-DMP)	11	9	0.500	80
Gezondheidscentrum Maarssenbroek (CV-DMP)	21	15	0.146	107
Rijnstate (CV-DMP)	17	13	0.227	151
Medisch Centrum Oud-West (CV-DMP)	17	12	1.000	17
Universiteit Medisch Centrum St. Radboud (CV-DMP)	32	22	0.125	54
Wijkgezondheidscentra Huizen (CV-DMP)	16	13	0.453	80
HAFANK (Hartfalen Noord Kennemerland) (Heart failure DMP)	15	15	1.000	20
Huisartsencoöperatie Midden-Brabant (COPD DMP)	40	32	0.118	82
Archiatros (COPD DMP)	40	30	0.002	161
Stichting Gezond Monnickendam (COPD DMP)	26	20	0.250	55
Zorggroep Almere (COPD DMP)	39	31	0.125	62
Huisartsen Coöperatie Zeist (Diabetes DMP)	19	13	0.125	97
Zorggroep Haaglanden (Diabetes DMP)	20	12	0.125	50
Gezondheidscentrum De Roerdomp (Diabetes DMP)	23	16	0.250	44
Chronische Ketenzorg Land van Cuijk en Noord Limburg BV (Co morbidity DMP)	8	6	0.625	91

Notes: M, mean; SD, standard deviation. [a]McNemar chi-square tests, T0 *vs*. T1. Analyses included respondents who completed questionnaires at both T0 and T1.

3: Short-Term Changes in Physical Quality of Life within each disease management programme

	Baseline (T0; 2010)		Follow-up (T1; 2011)		Short-term change			
	M	SD	M	SD	M	SD	p^{a}	n
Onze Lieve Vrouwe Gasthuis (CV-DMP)	41.26	(9.24)	41.42	(10.29)	+0.16	(5.88)	0.812	74
De Stichting Eerstelijns Samenwerkingsverband Achterveld (CV-DMP)	47.09	(7.91)	46.69	(7.84)	-0.39	(6.50)	0.642	60
Regionale Organisatie Huisartsen Amsterdam (CV-DMP)	41.97	(10.01)	40.79	(9.82)	-1.18	(5.51)	0.118	55
De Stichting Gezondheidscentra Eindhoven (CV-DMP)	46.23	(8.67)	45.01	(8.94)	-1.21	(7.09)	0.130	80
Gezondheidscentrum Maarssenbroek (CV-DMP)	45.54	(8.63)	45.81	(9.79)	+0.27	(7.77)	0.721	108
Rijnstate (CV-DMP)	44.07	(10.77)	43.21	(10.18)	-0.86	(7.04)	0.137	150
Medisch Centrum Oud-West (CV-DMP)	45.20	(10.43)	44.74	(9.93)	-0.45	(6.12)	0.751	19
Universiteit Medisch Centrum St. Radboud (CV-DMP)	41.04	(10.06)	41.18	(9.44)	+0.13	(8.83)	0.911	55
Wijkgezondheidscentra Huizen (CV-DMP)	43.53	(11.68)	41.60	(11.33)	-1.94	(7.08)	0.017	80
HAFANK (Hartfalen Noord Kennemerland) (Heart failure DMP)	34.89	(10.10)	31.10	(12.50)	-3.79	(8.99)	0.091	18
Huisartsencoöperatie Midden-Brabant (COPD DMP)	38.10	(10.17)	37.53	(11.35)	-0.57	(7.05)	0.456	86
Archiatros (COPD DMP)	39.95	(8.83)	39.30	(8.93)	-0.65	(7.13)	0.246	161
Stichting Gezond Monnickendam (COPD DMP)	38.76	(11.06)	37.67	(10.91)	-1.10	(7.53)	0.281	56
Zorggroep Almere (COPD DMP)	40.95	(9.84)	39.88	(9.47)	-1.07	(5.96)	0.159	63
Huisartsen Coöperatie Zeist (Diabetes DMP)	43.49	(9.88)	42.42	(9.92)	-1.07	(6.41)	0.101	98
Zorggroep Haaglanden (Diabetes DMP)	45.43	(9.59)	45.06	(9.58)	-0.36	(6.08)	0.672	51
Gezondheidscentrum De Roerdomp (Diabetes DMP)	41.28	(10.11)	40.63	(10.05)	-0.64	(6.81)	0.536	44
Chronische Ketenzorg Land van Cuijk en Noord Limburg BV (Co morbidity DMP)	42.34	(10.20)	41.75	(10.04)	-0.59	(6.37)	0.361	97

Notes: M, mean; SD, standard deviation. [a]Paired *t*-test, T0 *vs*. T1. Analyses included respondents who completed questionnaires at both T0 and T1.

4: Short-Term Changes in Mental Quality of Life within each disease management programme

	Baseline (T0; 2010)		Follow-up (T1; 2011)		Short-term change			
	M	SD	M	SD	M	SD	p^{a}	n
Onze Lieve Vrouwe Gasthuis (CV-DMP)	46.28	(11.61)	45.88	11.40	-0.39	7.17	0.637	74
De Stichting Eerstelijns Samenwerkingsverband Achterveld (CV-DMP)	52.29	(6.97)	52.50	(7.54)	+0.21	(6.27)	0.795	60
Regionale Organisatie Huisartsen Amsterdam (CV-DMP)	49.34	(10.23)	48.84	(9.86)	-0.51	(9.17)	0.687	55
De Stichting Gezondheidscentra Eindhoven (CV-DMP)	50.15	(9.63)	49.54	(9.70)	-061	(9.52)	0.569	80
Gezondheidscentrum Maarssenbroek (CV-DMP)	51.14	(8.09)	50.01	(9.47)	-1.14	(6.50)	0.072	108
Rijnstate (CV-DMP)	51.21	(8.98)	50.08	(9.51)	-1.13	(7.94)	0.082	150
Medisch Centrum Oud-West (CV-DMP)	48.48	(9.33)	47.57	(8.33)	-0.92	(9.23)	0.670	19
Universiteit Medisch Centrum St. Radboud (CV-DMP)	49.20	(11.59)	49.09	(9.03)	-0.10	(7.59)	0.919	55
Wijkgezondheidscentra Huizen (CV-DMP)	50.53	(8.39)	49.14	(9.37)	-1.39	(8.59)	0.153	80
HAFANK (Hartfalen Noord Kennemerland) (Heart failure DMP)	46.91	(6.91)	50.24	(7.24)	+3.33	(8.53)	0.116	18
Huisartsencoöperatie Midden-Brabant (COPD DMP)	47.20	(11.75)	46.61	(10.32)	-0.59	(9.11)	0.551	86
Archiatros (COPD DMP)	48.16	(10.10)	47.01	(10.78)	-1.15	(9.15)	0.113	161
Stichting Gezond Monnickendam (COPD DMP)	47.98	(10.22)	46.16	(9.80)	-1.82	(8.01)	0.095	56
Zorggroep Almere (COPD DMP)	49.88	(9.90)	48.39	(1.19)	-1.49	(9.32)	0.208	63
Huisartsen Coöperatie Zeist (Diabetes DMP)	51.91	(7.86)	51.49	(8.15)	-0.43	(6.29)	0.502	98
Zorggroep Haaglanden (Diabetes DMP)	49.01	(10.26)	47.81	(11.16)	-1.20	(7.74)	0.273	51
Gezondheidscentrum De Roerdomp (Diabetes DMP)	50.28	(6.00)	48.17	(7.58)	-2.12	(7.35)	0.063	44
Chronische Ketenzorg Land van Cuijk en Noord Limburg BV (Co morbidity DMP)	52.89	(7.92)	49.91	(8.56)	-2.98	(8.32)	0.001	97

Notes: M, mean; SD, standard deviation. [a]Paired *t*-test, T0 *vs*. T1. Analyses included respondents who completed questionnaires at both T0 and T1.

5: Long-Term Changes in Physical Activity within each disease management programme

	Baseline (T0; 2010)		Follow-up (T2; 2012)		Long-term change			
	M	SD	M	SD	M	SD	p^a	n
Onze Lieve Vrouwe Gasthuis (CV-DMP)	4.71	(2.07)	5.03	(2.21)	+0.32	(2.52)	0.482	31
De Stichting Eerstelijns Samenwerkingsverband Achterveld (CV-DMP)	5.74	(1.50)	5.48	(1.90)	-0.26	(1.64)	0.306	42
Regionale Organisatie Huisartsen Amsterdam (CV-DMP)	4.88	(2.30)	5.32	(2.19)	+0.44	(1.78)	0.229	25
De Stichting Gezondheidscentra Eindhoven (CV-DMP)	4.85	(2.02)	6.00	(1.36)	+1.15	(2.27)	0.001	52
Gezondheidscentrum Maarssenbroek (CV-DMP)	5.39	(1.80)	5.85	(1.64)	+0.46	(1.65)	0.079	41
Rijnstate (CV-DMP)	4.48	(2.38)	5.70	(1.59)	+1.22	(2.58)	<0.001	110
Medisch Centrum Oud-West (CV-DMP)	5.81	(1.87)	5.81	(1.94)	+0.00	(2.85)	1.000	16
Universiteit Medisch Centrum St. Radboud (CV-DMP)	5.55	(1.97)	6.00	(1.85)	+0.46	(0.96)	0.038	22
Wijkgezondheidscentra Huizen (CV-DMP)	4.75	(2.20)	5.49	(1.82)	+0.74	(2.30)	0.012	65
HAFANK (Hartfalen Noord Kennemerland) (Heart failure DMP)	5.75	(1.89)	6.50	(0.58)	+0.75	(1.50)	0.391	4
Huisartsencoöperatie Midden-Brabant (COPD DMP)	4.79	(2.04)	4.97	(2.02)	+0.18	(2.06)	0.482	68
Archiatros (COPD DMP)	4.71	(2.06)	5.49	(1.92)	+0.79	(2.17)	<0.001	130
Stichting Gezond Monnickendam (COPD DMP)	4.45	(2.33)	5.39	(2.05)	+0.94	(2.79)	0.062	33
Zorggroep Almere (COPD DMP)	5.32	(2.07)	6.10	(1.42)	+0.78	(2.09)	0.011	50
Huisartsen Coöperatie Zeist (Diabetes DMP)	5.09	(1.92)	5.80	(1.59)	+0.71	(1.84)	0.001	80
Zorggroep Haaglanden (Diabetes DMP)	4.44	(2.31)	5.67	(1.85)	+1.22	(2.10)	0.025	18
Gezondheidscentrum De Roerdomp (Diabetes DMP)	4.50	(1.87)	5.45	(1.70)	+0.95	(1.87)	0.004	38
Chronische Ketenzorg Land van Cuijk en Noord Limburg BV (Co morbidity DMP)	5.39	(1.86)	5.82	(1.69)	+0.42	(2.15)	0.092	76

Notes: M, mean; SD, standard deviation. [a]Paired *t*-test, T0 *vs*. T2. Analyses included respondents who completed questionnaires at both T0 and T2.

6: Long-Term Changes in Smoking within each disease management programme

	Baseline (T0; 2010)	Follow-up (T2; 2012)		
	%	%	p[a]	n
Onze Lieve Vrouwe Gasthuis (CV-DMP)	20	16	0.625	51
De Stichting Eerstelijns Samenwerkingsverband Achterveld (CV-DMP)	18	18	1.000	51
Regionale Organisatie Huisartsen Amsterdam (CV-DMP)	31	22	0.250	32
De Stichting Gezondheidscentra Eindhoven (CV-DMP)	15	8	0.125	62
Gezondheidscentrum Maarssenbroek (CV-DMP)	18	11	0.375	45
Rijnstate (CV-DMP)	13	9	0.125	138
Medisch Centrum Oud-West (CV-DMP)	17	11	1.000	18
Universiteit Medisch Centrum St. Radboud (CV-DMP)	24	24	1.000	25
Wijkgezondheidscentra Huizen (CV-DMP)	14	16	1.000	97
HAFANK (Hartfalen Noord Kennemerland) (Heart failure DMP)	18	36	0.500	11
Huisartsencoöperatie Midden-Brabant (COPD DMP)	44	33	0.021	86
Archiatros (COPD DMP)	44	35	0.007	151
Stichting Gezond Monnickendam (COPD DMP)	30	18	0.125	44
Zorggroep Almere (COPD DMP)	36	29	0.219	62
Huisartsen Coöperatie Zeist (Diabetes DMP)	16	14	0.687	99
Zorggroep Haaglanden (Diabetes DMP)	26	9	0.125	23
Gezondheidscentrum De Roerdomp (Diabetes DMP)	26	19	0.250	47
Chronische Ketenzorg Land van Cuijk en Noord Limburg BV (Co morbidity DMP)	8	6	0.500	99

Notes: M, mean; SD, standard deviation. [a]McNemar chi-square tests, T0 *vs.* T2. Analyses included respondents who completed questionnaires at both T0 and T2.

7: Long-Term Changes in Physical Quality of Life within each disease management programme

	Baseline (T0; 2010)		Follow-up (T2; 2012)		Long-term change			
	M	SD	M	SD	M	SD	p^a	n
Onze Lieve Vrouwe Gasthuis (CV-DMP)	41.73	(7.89)	43.29	(7.54)	+1.56	(6.64)	0.100	51
De Stichting Eerstelijns Samenwerkingsverband Achterveld (CV-DMP)	46.79	(8.16)	48.31	(7.89)	+1.53	(6.42)	0.103	49
Regionale Organisatie Huisartsen Amsterdam (CV-DMP)	42.25	(8.44)	42.78	(8.05)	+0.53	(4.91)	0.538	33
De Stichting Gezondheidscentra Eindhoven (CV-DMP)	46.94	(9.55)	48.69	(7.36)	+1.76	(7.41)	0.074	59
Gezondheidscentrum Maarssenbroek (CV-DMP)	45.51	(8.90)	46.00	(9.08)	+0.49	(6.83)	0.630	46
Rijnstate (CV-DMP)	44.52	(10.30)	45.70	(9.22)	+1.18	(6.07)	0.024	138
Medisch Centrum Oud-West (CV-DMP)	45.60	(11.38)	46.01	(10.17)	+1.41	(5.57)	0.312	17
Universiteit Medisch Centrum St. Radboud (CV-DMP)	43.24	(11.02)	44.35	(7.46)	+1.12	(7.54)	0.516	20
Wijkgezondheidscentra Huizen (CV-DMP)	42.95	(11.36)	44.05	(8.86)	+1.10	(9.26)	0.253	94
HAFANK (Hartfalen Noord Kennemerland) (Heart failure DMP)	37.94	(10.13)	37.10	(12.69)	-0.84	(7.02)	0.728	9
Huisartsencoöperatie Midden-Brabant (COPD DMP)	38.97	(10.46)	41.88	(8.49)	+2.92	(6.90)	<0.001	89
Archiatros (COPD DMP)	40.06	(8.87)	43.19	(7.76)	+3.13	(7.24)	<0.001	143
Stichting Gezond Monnickendam (COPD DMP)	39.68	(11.56)	40.19	(9.36)	+0.51	(6.79)	0.604	49
Zorggroep Almere (COPD DMP)	39.92	(10.28)	41.59	(9.54)	+1.68	(8.42)	0.119	63
Huisartsen Coöperatie Zeist (Diabetes DMP)	42.66	(10.46)	44.29	(9.66)	+1.63	(7.30)	0.029	99
Zorggroep Haaglanden (Diabetes DMP)	45.75	(8.95)	46.95	(7.50)	+1.21	(9.44)	0.565	21
Gezondheidscentrum De Roerdomp (Diabetes DMP)	42.48	(10.53)	44.10	(8.23)	+1.62	(6.04)	0.076	46
Chronische Ketenzorg Land van Cuijk en Noord Limburg BV (Co morbidity DMP)	41.30	(10.61)	42.46	(8.85)	+1.16	(6.42)	0.086	92

Notes: M, mean; SD, standard deviation. [a]Paired *t*-test, T0 *vs*. T2. Analyses included respondents who completed questionnaires at both T0 and T2.

8: Long-Term Changes in Mental Quality of Life within each disease management programme

	Baseline (T0; 2010)		Follow-up (T2; 2012)		Long-term change			
	M	SD	M	SD	M	SD	*p*[a]	*n*
Onze Lieve Vrouwe Gasthuis (CV-DMP)	46.51	(11.32)	44.61	(10.42)	-1.90	(6.59)	0.045	51
De Stichting Eerstelijns Samenwerkingsverband Achterveld (CV-DMP)	50.60	(7.28)	51.43	(7.33)	+0.83	(5.39)	0.285	49
Regionale Organisatie Huisartsen Amsterdam (CV-DMP)	51.24	(10.45)	49.59	(11.67)	-1.65	(11.68)	0.422	33
De Stichting Gezondheidscentra Eindhoven (CV-DMP)	50.26	(8.99)	48.02	(10.11)	-2.29	(9.60)	0.078	59
Gezondheidscentrum Maarssenbroek (CV-DMP)	51.18	(7.98)	48.81	(10.61)	-2.37	(6.94)	0.025	46
Rijnstate (CV-DMP)	50.76	(10.12)	49.49	(9.60)	-1.27	(8.14)	0.069	138
Medisch Centrum Oud-West (CV-DMP)	48.10	(9.28)	48.53	(7.16)	+0.43	(6.65)	0.792	17
Universiteit Medisch Centrum St. Radboud (CV-DMP)	49.25	(13.17)	47.58	(11.12)	-1.67	(10.49)	0.485	20
Wijkgezondheidscentra Huizen (CV-DMP)	50.27	(7.70)	50.56	(8.22)	+0.29	(8.18)	0.732	94
HAFANK (Hartfalen Noord Kennemerland) (Heart failure DMP)	48.63	(6.13)	50.30	(6.22)	+1.67	(5.56)	0.395	9
Huisartsencoöperatie Midden-Brabant (COPD DMP)	47.03	(11.17)	46.20	(11.11)	-0.83	(10.28)	0.450	89
Archiatros (COPD DMP)	48.15	(10.45)	45.92	(10.64)	-2.23	(11.05)	0.017	143
Stichting Gezond Monnickendam (COPD DMP)	48.81	(10.23)	47.68	(9.76)	-1.13	(6.91)	0.259	49
Zorggroep Almere (COPD DMP)	50.51	(9.70)	49.22	(8.36)	-1.29	(8.31)	0.222	63
Huisartsen Coöperatie Zeist (Diabetes DMP)	51.95	(8.80)	50.74	(8.38)	-1.21	(8.02)	0.136	99
Zorggroep Haaglanden (Diabetes DMP)	48.49	(9.49)	50.29	(7.41)	+1.80	(9.39)	0.391	21
Gezondheidscentrum De Roerdomp (Diabetes DMP)	49.43	(9.04)	48.20	(8.75)	-1.23	(8.80)	0.348	46
Chronische Ketenzorg Land van Cuijk en Noord Limburg BV (Co morbidity DMP)	51.52	(9.14)	50.37	(8.52)	-1.15	(7.80)	0.160	92

Notes: M, mean; SD, standard deviation. [a]Paired *t*-test, T0 *vs*. T2. Analyses included respondents who completed questionnaires at both T0 and T2.

9: Sustainable Changes in Physical Activity within each disease management programme

	Baseline (T0; 2010)		Follow-up (T3; 2013)		Sustainable change			
	M	SD	M	SD	M	SD	p^a	n
Onze Lieve Vrouwe Gasthuis (CV-DMP)	5.30	(2.34)	5.65	(2.04)	+0.35	(1.72)	0.343	23
Gezondheidscentrum Maarssenbroek (CV-DMP)	5.05	(2.01)	5.87	(1.71)	+0.82	(2.07)	0.020	38
Huisartsencoöperatie Midden-Brabant (COPD DMP)	4.98	(1.96)	5.34	(2.18)	+0.36	(1.97)	0.167	58
Archiatros (COPD DMP)	4.84	(2.06)	5.40	(1.92)	+0.56	(2.15)	0.013	95
Stichting Gezond Monnickendam (COPD DMP)	4.46	(2.27)	5.66	(1.86)	+1.20	(2.77)	0.015	35
Huisartsen Coöperatie Zeist (Diabetes DMP)	5.16	(1.87)	5.80	(1.55)	+0.64	(1.97)	0.004	81
Chronische Ketenzorg Land van Cuijk en Noord Limburg BV (Co morbidity DMP)	5.43	(1.67)	5.86	(1.65)	+0.43	(2.07)	0.087	70

Notes: M, mean; SD, standard deviation. [a]Paired *t*-test, T0 *vs*. T3. Analyses included respondents who completed questionnaires at both T0 and T3.

10: Sustainable Changes in Smoking within each disease management programme

	Baseline (T0; 2010)	Follow-up (T3; 2013)		
	%	%	p^{a}	*n*
Onze Lieve Vrouwe Gasthuis (CV-DMP)	18	18	1.000	28
Gezondheidscentrum Maarssenbroek (CV-DMP)	18	10	0.250	40
Huisartsencoöperatie Midden-Brabant (COPD DMP)	49	33	0.003	67
Archiatros (COPD DMP)	46	36	0.029	115
Stichting Gezond Monnickendam (COPD DMP)	23	13	0.063	48
Huisartsen Coöperatie Zeist (Diabetes DMP)	17	14	0.687	90
Chronische Ketenzorg Land van Cuijk en Noord Limburg BV (Co morbidity DMP)	7	5	0.625	83

Notes: M, mean; SD, standard deviation. [a]McNemar chi-square tests, T0 *vs*. T3. Analyses included respondents who completed questionnaires at both T0 and T3.

11: Sustainable Changes in Physical Quality of Life within each disease management programme

	Baseline (T0; 2010)		Follow-up (T3; 2013)		Sustainable change			
	M	SD	M	SD	M	SD	p^a	n
Onze Lieve Vrouwe Gasthuis (CV-DMP)	41.58	(8.83)	43.97	(8.54)	+2.39	(6.15)	0.045	29
Gezondheidscentrum Maarssenbroek (CV-DMP)	44.94	(8.62)	46.97	(7.91)	+2.03	(5.48)	0.028	38
Huisartsencoöperatie Midden-Brabant (COPD DMP)	38.55	(10.71)	39.38	(8.07)	+0.83	(6.60)	0.294	71
Archiatros (COPD DMP)	40.90	(8.63)	42.62	(8.29)	+1.72	(7.32)	0.016	109
Stichting Gezond Monnickendam (COPD DMP)	40.51	(10.80)	40.35	(8.84)	-0.16	(7.23)	0.880	48
Huisartsen Coöperatie Zeist (Diabetes DMP)	42.76	(10.04)	43.69	(9.15)	+0.93	(6.93)	0.206	91
Chronische Ketenzorg Land van Cuijk en Noord Limburg BV (Co morbidity DMP)	41.73	(10.20)	43.33	(8.33)	+1.60	(5.67)	0.014	79

Notes: M, mean; SD, standard deviation. [a]Paired *t*-test, T0 *vs*. T3. Analyses included respondents who completed questionnaires at both T0 and T3.

12: Sustainability in Mental Quality of Life within each disease management programme

	Baseline (T0; 2010)		Follow-up (T3; 2013)		Sustainable change			
	M	SD	M	SD	M	SD	p[a]	n
Onze Lieve Vrouwe Gasthuis (CV-DMP)	48.04	(12.82)	46.22	(12.37)	-1.82	(7.73)	0.216	29
Gezondheidscentrum Maarssenbroek (CV-DMP)	50.85	(9.24)	50.56	(8.37)	-0.29	(6.77)	0.795	38
Huisartsencoöperatie Midden-Brabant (COPD DMP)	48.22	(10.78)	47.35	(10.70)	-0.87	(7.88)	0.358	71
Archiatros (COPD DMP)	48.90	(9.55)	46.69	(9.89)	-2.21	(9.78)	0.020	109
Stichting Gezond Monnickendam (COPD DMP)	48.61	(9.82)	46.56	(10.80)	-2.05	(6.75)	0.041	48
Huisartsen Coöperatie Zeist (Diabetes DMP)	52.05	(8.34)	50.15	(8.52)	-1.90	(7.03)	0.012	91
Chronische Ketenzorg Land van Cuijk en Noord Limburg BV (Co morbidity DMP)	51.68	(8.64)	49.02	(9.10)	-2.67	(7.04)	0.001	79

Notes: M, mean; SD, standard deviation. [a]Paired *t*-test, T0 *vs*. T3. Analyses included respondents who completed questionnaires at both T0 and T3.

Appendix Chapter 7

1: Differences in costs between T2 and T0

DMP		primary care	Policlinic department	Hospital admissions	medication	total costs HP	travelling	productivity	total costs SP
1	mean	42	-28	643	-107*	535	-71**	-3064	-294
	SD	1399	1673	9874	445	11629	256	13077	18619
	n	58	55	58	56	58	58	34	58
2	mean	77	72	-55	-132**	-38	-144**	-41	1057
	SD	819	450	4874	289	5352	502	201	10184
	n	51	51	51	51	51	51	24	51
3	mean	11	-200	845	-90	600	-32**		-28
	SD	965	697	9133	329	9826	69		10976
	n	33	29	33	33	33	33		33
4	mean	-24	-36	60	-70*	-71	-27	1744	813
	SD	880	917	1471	279	2317	96	14351	10067
	n	64	59	64	63	64	64	26	64
5	mean	-139	21	19*	-179	-260	-3	1804	-622
	SD	1221	818	2722	580	3776	145	10344	14267
	n	47	43	47	47	47	47	22	47
6	mean	-74	-76	419	-128	185	-883**		-699
	SD	838	370	22228	443	21763	2851		21980
	n	13	12	13	12	13	13		13
8	mean	43	131	-820	-62**	-708	-27**	-668	-1456
	SD	1428	1115	6783	314	7371	100	3309	9399
	n	147	137	147	145	147	147	68	147
9	mean	-117	-16	0	-115*	-241	-28	-8674*	-5007
	SD	534	399	208	133	766	56	18923	14547
	n	20	19	20	19	20	20	11	20
10	mean	175	-129	2586	-112	2521	-40*		-1122
	SD	478	776	16585	397	16871	127		22871
	n	26	26	26	26	26	26		26
11	mean	168	-42	3228	-113*	3254	-182*	152	3619
	SD	1082	701	20379	344	21094	1693	8737	22928
	n	104	95	104	102	104	104	58	104
12	mean	261	25	-4238	-108	-4088	-317*	-854	-5336
	SD	1891	884	21982	504	22015	2060	6393	23711
	n	93	87	93	83	93	93	56	93
13	mean	-81	-53	1184	-20	977	-75*	266	563
	SD	1405	816	11789	470	11930	324	7436	13374
	n	160	150	160	142	160	160	89	160
14	mean	176	38	-758	86	-473	-14	2090	742

	SD	1150	774	10436	468	10282	270	11446	13788
	n	51	48	51	50	51	51	30	51
15	mean	29	-46	881	-39	805	-104*	326	627
	SD	1094	1091	10346	449	10730	339	5608	12023
	n	152	140	152	149	152	152	90	152
16	mean	-114	-193	-2512	63	-2826	-173*		-3404
	SD	1806	1848	14057	419	14851	1097		15429
	n	68	63	68	63	68	68		68
17	mean	-196	34	238	-98**	-26	-106*	165	-165
	SD	1657	828	3983	397	4568	419	1279	5121
	n	103	100	103	103	103	103	60	103
18	mean	252	235	1481	65	2049	-51		1998
	SD	993	963	5116	555	6104	227		6052
	n	23	22	23	23	23	23		23
19	mean	204	111	-471	-192*	-364	-114*	2136	-1489
	SD	1580	708	7925	532	8837	486	11135	17330
	n	48	44	48	48	48	48	23	48
CV	mean	45	11	635	-100*	595**	-71*	-534	167**
	SD	1150	977	11084	359	11711	760	8990	15448
	n	550	514	550	542	550	550	285	550
COPD	mean	34	-46	-1113	-10	-1184	-145**	183	-1612
	SD	1589	1085	15325	473	15490	1156	7265	17075
	n	372	348	372	338	372	372	211	372
DM	mean	-26	81	207	-103**	155	-101**	628	-244*
	SD	1570	815	5485	464	6231	418	5578	10140
	n	174	166	174	174	174	174	94	174
Total	mean	29	-4	88	-68*	31*	-109*	-37	-368*
	SD	1345	999	12041	422	12438	876	7618	15052
	n	29,63807	-2,87192	88,80239	-67,2315	31,66011	-108,1594	-35,57336	-367,14575

Costs and QALYs per year (complete cases in T0, T1, T2)

DMP		Total healthcare costs			Total societal costs			QALYs	
		Year 0	Year 1	Year 2	Year 0	Year 1	Year 2	Year 1	Year 2
1	mean	3195	5922	5541	5305	6167	5715	0,75	0,68
	SD	6135	14225	14702	15706	14212	14684	0,21	0,20
	n	29	29	29	29	29	29	25	22
2	mean	1684	1336	1627	1889	2265	1757	0,86	0,86
	SD	4819	1515	3029	4850	5445	3529	0,13	0,14
	n	46	46	46	46	46	46	46	40
3	mean	2345	2138	2888	3278	2331	3080	0,84	0,81
	SD	4574	3845	9471	6755	3927	9485	0,12	0,10
	n	28	28	28	28	28	28	28	26
4	mean	1339	1351	1149	2179	3039	2419	0,83	0,81
	SD	2590	1982	2197	7876	8775	7973	0,17	0,15
	n	56	56	56	56	56	56	51	42
5	mean	1618	1337	1029	1663	1371	1052	0,83	0,80
	SD	1667	1251	1261	1697	1237	1319	0,18	0,25
	n	12	12	12	12	12	12	12	9
6	mean	8243	7668	1864	8396	7841	1894	0,71	0,72
	SD	18314	13791	1396	18350	13735	1428	0,29	0,30
	n	8	8	8	8	8	8	7	7
8	mean	1831	1740	1759	2654	2244	2049	0,81	0,76
	SD	4188	2604	2884	6815	3776	3493	0,20	0,21
	n	125	125	125	125	125	125	117	96
9	mean	1205	1029	1035	6785	4928	1326	0,84	0,73
	SD	1684	1087	1421	16252	14331	1598	0,18	0,29
	n	18	18	18	18	18	18	16	9
10	mean	3171	1409	6925	8177	1447	6941	0,81	0,75
	SD	7108	1319	26387	17915	1326	26407	0,10	0,17
	n	19	19	19	19	19	19	15	13
11	mean	1385	4554	6163	1770	6977	8097	0,82	0,75
	SD	1369	8187	25455	2141	16546	27080	0,17	0,22
	n	70	70	70	70	70	70	62	53
12	mean	1966	24640	3107	5622	24734	3232	0,68	0,69
	SD	1282	73795	2586	13298	73837	2656	0,20	0,18
	n	14	14	14	14	14	14	11	10
13	mean	2443	3289	3159	3749	3797	5156	0,72	0,74
	SD	2284	5767	4325	5687	5907	11310	0,21	0,22
	n	36	36	36	36	36	36	31	30
14	mean	2271	2704	2795	2318	2736	2810	0,87	0,84
	SD	1100	2333	981	1137	2314	975	0,10	0,13
	n	5	5	5	5	5	5	5	5
15	mean	4388	3960	4930	5053	4251	6992	0,77	0,73
	SD	10521	4917	9006	10798	4995	13999	0,22	0,26
	n	32	32	32	32	32	32	29	29

|									
16	mean	5924	3790	2537	6792	3964	2724	0,80	0,75
	SD	17214	7760	2102	17831	7769	2293	0,19	0,23
	n	54	54	54	54	54	54	51	49
17	mean	1689	2765	1209	3393	3085	1276	0,85	0,84
	SD	1595	3843	1202	6643	3915	1290	0,16	0,15
	n	10	10	10	10	10	10	8	7
18	mean	1804	1726	4244	1959	2010	4325	0,83	0,80
	SD	1109	1120	7379	1366	1226	7401	0,11	0,16
	n	16	16	16	16	16	16	16	15
19	mean	3879	2435	3764	7089	4620	5543	0,81	0,81
	SD	6207	1954	8015	15567	11588	11590	0,19	0,17
	n	35	35	35	35	35	35	35	29
CV	mean	1831	2398	2964	2996	3524	3622	0,82	0,78
	SD	4008	5651	13124	8659	9643	14082	0,17	0,20
	n	403	403	403	403	403	403	372	310
COPD	mean	4099	6253	2827	5432	6520	3596	0,76	0,74
	SD	12275	27321	3026	13790	27327	6794	0,20	0,22
	n	109	109	109	109	109	109	98	94
DMP	mean	2976	2303	3471	5138	3684	4524	0,82	0,81
	SD	4862	2197	7162	12240	8949	9614	0,17	0,16
	n	61	61	61	61	61	61	59	51
Total	mean	2565	3224	3079	3820	4167	3861	0,81	0,77
	SD	7091	12611	11142	10426	14339	12573	0,18	0,20
	n	613	613	613	613	613	613	565	491

Appendix Chapter 8

1: The cost-effectiveness planes per disease

Healthcare perspective
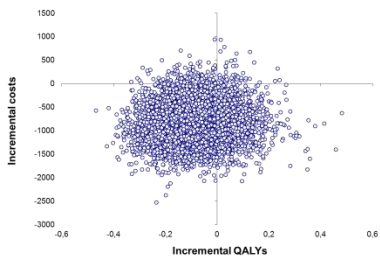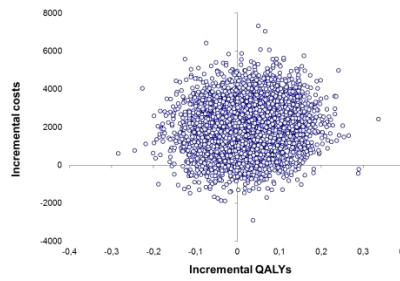
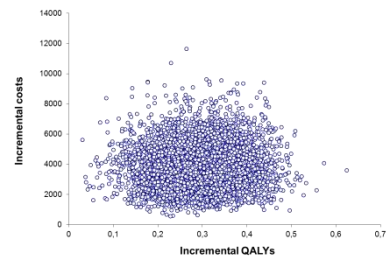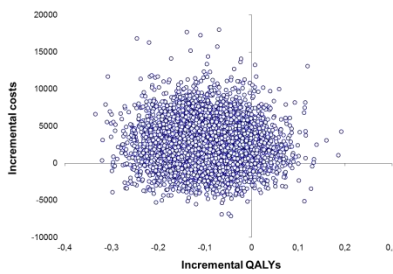CV- primary prevention   CV- secondary prevention   CV- both preventions
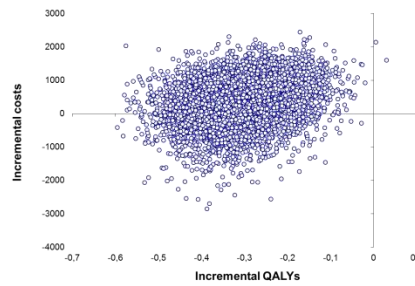

COPD   DM

Societal perspective

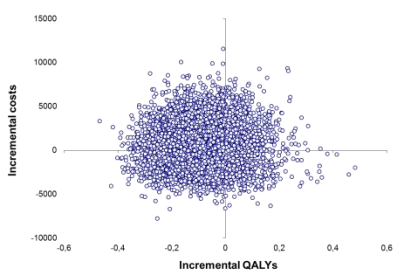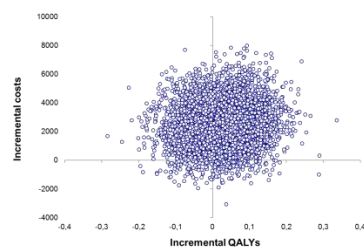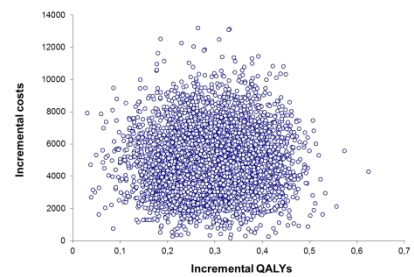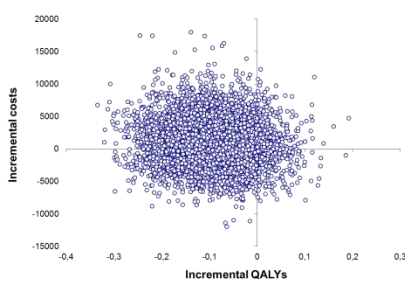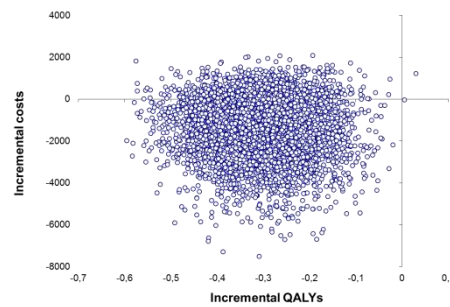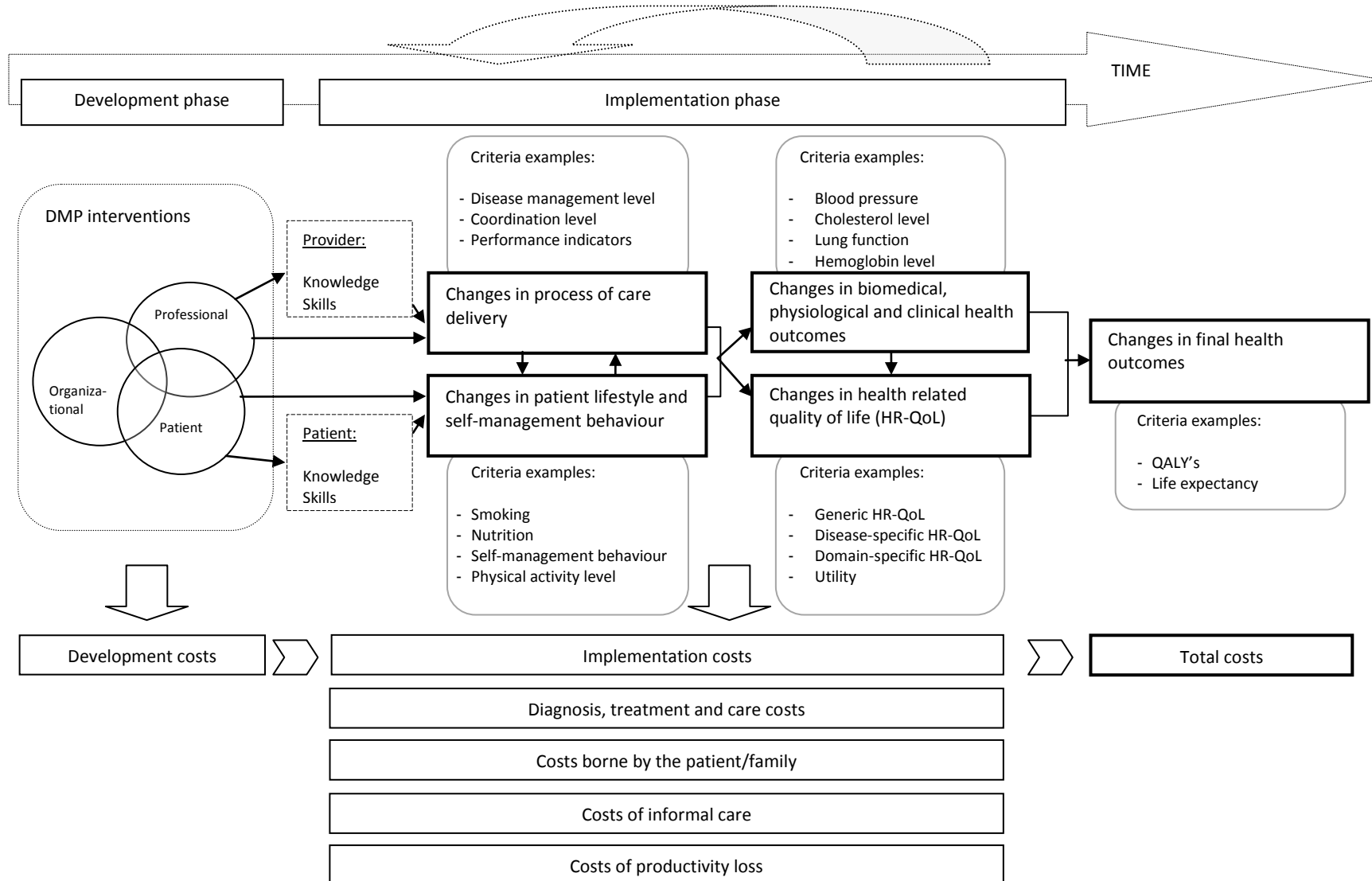CV- primary prevention   CV- secondary prevention   CV- both preventions

COPD   DM

Appendix Chapter 10

1: Framework for the economic evaluation of DMPs

TIME

Development phase	Implementation phase

DMP interventions

Professional

Organiza-tional

Patient

Provider:

Knowledge
Skills

Patient:

Knowledge
Skills

Criteria examples:

- Disease management level
- Coordination level
- Performance indicators

Criteria examples:

- Blood pressure
- Cholesterol level
- Lung function
- Hemoglobin level

Changes in process of care delivery

Changes in biomedical, physiological and clinical health outcomes

Changes in final health outcomes

Changes in patient lifestyle and self-management behaviour

Changes in health related quality of life (HR-QoL)

Criteria examples:

- QALY's
- Life expectancy

Criteria examples:

- Smoking
- Nutrition
- Self-management behaviour
- Physical activity level

Criteria examples:

- Generic HR-QoL
- Disease-specific HR-QoL
- Domain-specific HR-QoL
- Utility

Development costs		Implementation costs		Total costs

Diagnosis, treatment and care costs

Costs borne by the patient/family

Costs of informal care

Costs of productivity loss

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